



# Direct Payments Pure Dead Brilliant!



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# Foreword



Etienne d'Aboville  
Chief Executive

Disabled people and their organisations campaigned long and hard over many years to have more control over their support arrangements. Scotland's Self-directed Support (SDS) legislation now gives people 4 options to choose from. But what's the right option and what are the pros and cons of each? It can all be a bit confusing. The aim of this book is to show how some disabled people and carers living in Glasgow have used the first of these options - a direct payment - to create support packages that suit their particular needs. For many, a direct payment offers the most control and flexibility. And yet some people don't even consider them because they're put off by the idea that they're too complicated or difficult to manage. I hope the accounts in this book will go some way to show that a direct payment can be the best option and often repays any extra effort that might be involved.

I'd like to thank Lilian Smith for her sterling work in co-ordinating this booklet with the support of our team of Inclusive Living Advisers with a particular mention for Leigh Rennie who on several occasions proof read all 36 pages. I would also like to thank Norma Curran and Values Into Action for collaborating with us on the project; Robbie Robertson and David Ross from VIA who helped us with the interviews; Garry McCann and Simon Alderson from Cole AD for the book's imaginative design and layout and, of course, the Scottish Government for funding it. Most of all though, I'd like to thank all the participants who so willingly gave up their time to tell us their stories so that others could learn from their experiences. I hope that, after reading their accounts, you too will agree that direct payments can indeed be **'pure dead brilliant'**!



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# Edward's Story



**My name  
is Edward,  
I am 75  
years of  
age and  
I have  
Cerebral  
Palsy**

I was born in Glasgow and lived with my family on the third floor of a tenement building. After the death of my father, my mother found it difficult to provide all of the practical assistance I required with washing, dressing, having my meals and in particular getting me up and down stairs. She approached the local Social Work Department for support. Unfortunately, at that time, they were unable to arrange alternative accommodation for us or provide assistance with personal care. As a result, I was admitted into residential care at the age of thirteen.

I spent all of my early life in a long stay hospital. This was not a pleasant experience and I constantly asked to go home. I was given very little formal education and as a result I am unable to read or write. In my early forties, as the result of a hospital closure programme, I was offered the tenancy of a flat in a sheltered housing complex. My personal care was provided by the Council's Home Help Service, as it was then called, and I attended a sheltered workshop.

Although this was much better than my life in hospital, I still felt this was not how I wanted to live my life.

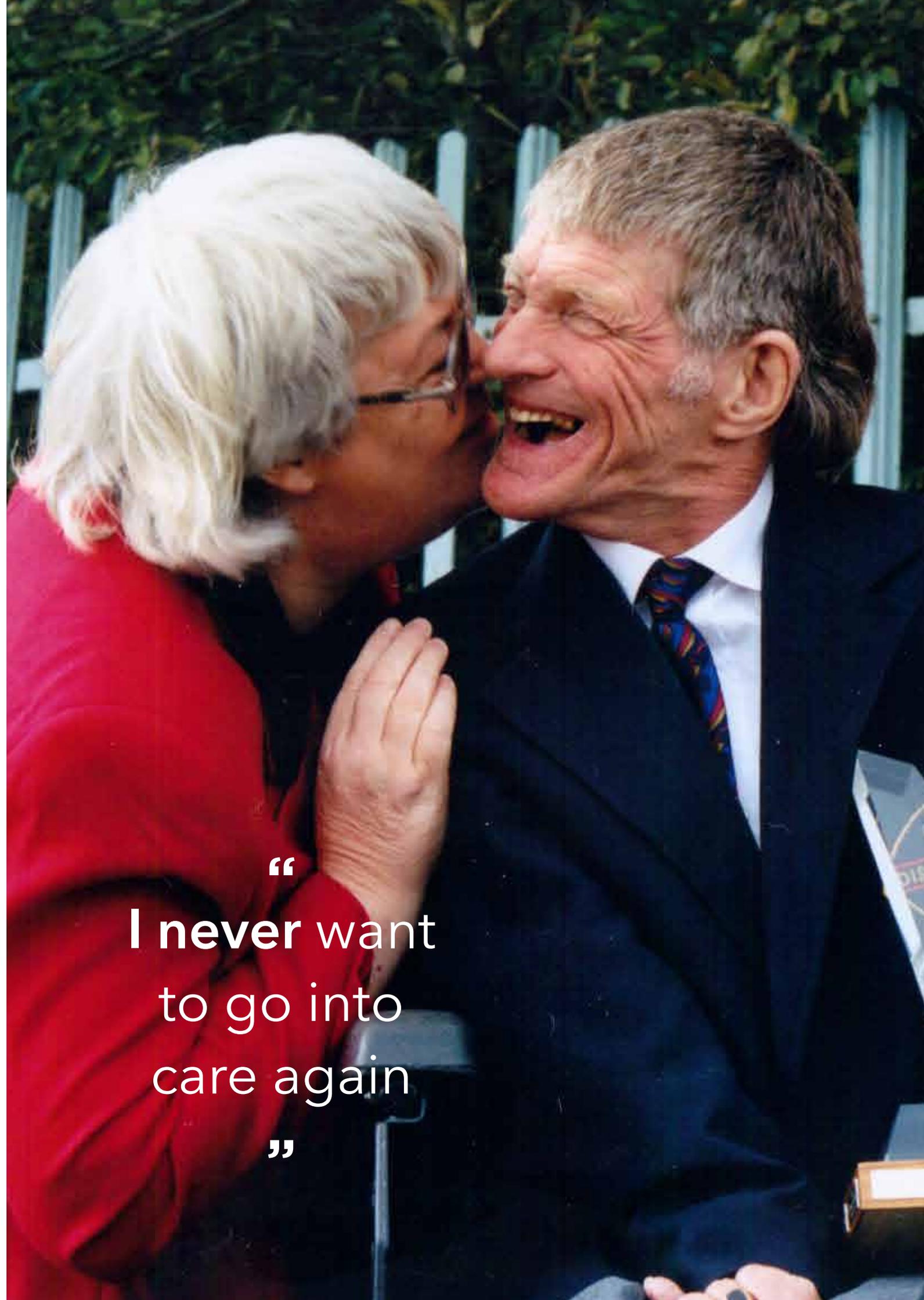
Whilst I appreciated the support provided by the home help service, it did restrict my choice over basic things such as when to get up, go to bed or have my meals. Also the activities at the sheltered workshop were very boring and my support at that time did not allow me to get involved in my local community. I wanted to be able to drop into my local pub for a pint, go to the cinema with a couple of friends or go on holiday. Things that other people take for granted.

Having a direct payment has given me the opportunity to choose and control my own support arrangements. I really appreciated the support provided by GCIL who helped me to prepare for my assessment. I was then able to explain to my social worker exactly

how I would like to use my direct payment and assure him that GCIL could support me to carry out safe recruitment. He was really impressed that I was so well prepared!

Direct payments have changed my life. I now employ three personal assistants (PAs) who provide my support. I chose PAs who share my interests and are fully committed to providing the support I need to lead a full and active life. I am an active member of People First, I go along to support my favourite football team each week and I go on holiday every year. Having the opportunity to get out and about in my local community has enabled me to make some really close friendships with people who enjoy my company. I am not just meeting people who are paid to spend time with me.

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“  
**I never want  
to go into  
care again**  
”



# Tricia's Story

My name is Tricia and I live with my husband, son Jordan and his older sister in the north of Glasgow

Jordan has complex learning disabilities and Autism. He is 20 years old and a strapping 6 feet 3 inches!

Jordan left Milton school 2 years ago. During his time at school Jordan attended a club once a week and also went to a respite resource 1-2 nights every few weeks. However sometimes he would not settle at respite and we would have to collect him early.

Jordan loves outdoor activities and being "on the go" and we wanted him to have more of those kinds of opportunities when he left school rather than spending all his time in a day centre, so we opted to apply for a direct payment. In preparation for leaving school a social worker was allocated and although the social worker was new and inexperienced, with her help things initially went smoothly. Jordan was allocated a budget in May 2012 just before he left school and it looked like it was "all systems go." At that point the social worker asked me if I had welfare and financial guardianship. We did have welfare guardianship but not financial - we had never been told that we would need both. Things ground to a halt and we were left to sort it all out.



Jordan was attending a day centre called Sense Touchbase two days a week at this time and we intended to employ personal assistants (PAs) to provide all the other support. What we did, thanks to the help of an advocacy worker, was to arrange for a voluntary care organisation to employ the PAs we identified on a temporary basis. Social Work Services arranged payment to the organisation and when the guardianship order came through we then employed the PAs ourselves - unusual I know but barriers can almost always be overcome!

The PAs we employed already knew Jordan as they also worked in the club he attended. He had built up good relationships with them which was such an important feature of our decision to employ them as Jordan has difficulty adapting to new people and situations. By the way, the club did not suffer a sudden loss of staff as the hours are complimentary so they can do both jobs.

The PAs have been fantastic for Jordan. He has been out and about doing the things that he enjoys just like any other young person. He has enjoyed a wide range of activities including a speedboat ride on Loch Lomond, skiing at Xcape's Snow Zone, shows, discos and the pub. He has been away for weekends with his PAs to an outdoor activity centre at Lochgoilhead (which he loves and is cheaper than his old respite which everyone accepted Jordan had grown out of). He has even been away a "lads weekend" with a friend and their PAs. Let's face it, what 20 year old wants to go everywhere with their parents??

Direct payments have also benefited us as a family. Because we know that Jordan is happy doing the things he enjoys, my husband and I can enjoy relaxed time together, and with our daughter, without having to check my phone worrying that he is unhappy somewhere and wanting to come home.

Managing a direct payment can be hard to start with but with GCIL's help you can take whatever level of responsibility you're comfortable with.

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and about  
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he enjoys** just  
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young person

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I live in  
my own  
home and  
manage 2  
personal  
assistants

# M's Story



I live in my own home and manage two personal assistants (PAs) and occasionally agency support workers and this has opened up so many new opportunities for me to do the things I want to do at home and in the community. Before I had a direct payment I was really restricted but I never realised I was restricted because I had never known it any other way.

I found the experience of applying for direct payments hard and depressing even though I knew why the social worker had to ask all the questions they were asking.

I felt that they asked personal questions that had little to do with the direct payment. However I'm glad that I saw it through as otherwise I wouldn't have the payment to this day.



Once my direct payment was approved I decided to employ my own PAs as well as an agency. I know the PAs better, so I give them different tasks. I only use the agency for cover in case someone is sick or on holiday. My PAs know me really well e.g. when we are out they know before anyone else when I'm getting annoyed and when to just give me a bit of space. Because of my PAs I can go on holiday, which I was never able to do before.

I have a meeting with my staff once a week where we work out when they will come to work and when to take time off.

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**Before I had a direct payment I was really restricted but I never realised I was restricted because I had never known it any other way**

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I've always got someone with me but if a PA wants to go somewhere or do something for personal reasons the PAs swap. It's about come and go – like a marriage without the fighting! Irene my PA says that although we have a friendly relationship she never forgets that I am the boss. Occasionally Irene arranges surprise “mystery tours” which I enjoy and I have visited some really interesting places which have helped me to broaden my horizons. I am open to the PAs making suggestions about what we might do or where to go but the final decision is always mine.



GCIL helped me to get my direct payment and then employ the staff. They manage the bank account on my behalf and pay my PAs. They also let me know about different training days that other organisations offer to develop my skills and abilities.

I have a much better life now because I can come and go as I like and I control the support I get. I regularly go out to the local sports centre and library which I enjoy. I have been helped to develop new skills like going shopping, managing my own money and handling my own diet. I understand money a lot more now

since I got my direct payment. I don't have anyone to answer to apart from myself as long as I spend the money as I am supposed to. I have a lot more freedom. If I want to stay in and watch the soaps in my pyjamas I can. I feel like I don't have a restricted life and I can be my own person. I can make my own choices about what I want to do with my life.

I would recommend direct payments to anyone. Go for it. There may be some problems along the way, but there will have been someone before with that problem and they will know how it can be solved!

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Jamie was  
my school  
friend and  
now 45  
years later  
he is my  
PA!

I found out about direct payments when I went to a meeting about Self-directed Support. It took me about a year from hearing about direct payments to getting my first payment. I met with a social worker and we worked together for a while until it was approved. I got a big enough budget to cover the number of hours I needed.

I didn't set out to get a personal assistant. I was getting support from Cordia, but I wasn't happy with the support I was receiving, because they didn't have enough time to do the things I needed them to do. Jamie started coming to see me more and more frequently so when I was told that a PA could be a friend, or in exceptional cases a family member, we started looking more into it. Jamie knows me so well that I thought why couldn't he become my PA? And the rest is history! My support now is really flexible. Jamie helps me with everything from shopping and handling my money to personal care, like getting washed and dressed. It's good to have Jamie as my PA because I don't get embarrassed about asking him to do certain things because I have known him since school. We go out and about a lot which is great. At other times it's just "chewing the fat" with some mates over a glass of wine.

# Jim's Story



Before I got my direct payment the support I got didn't match what my support needs were, so I had to depend on Jamie, my friend that I have known since school, to pop in and help me with some things like going to the shops or giving the house a tidy up.

Before my direct payment I only received support from Cordia, for one hour on Tuesday and Thursday. When they came in there wasn't time to do much. They usually cleaned a bit, made a meal and sometimes they would bring me in a few bits and bobs like bread, milk and sugar. I suppose it was nice to see new people as I didn't really get out much. That was the only "professional" support that I received.

GCIL help me with all the admin work and they helped me to attend training courses so I could start doing it for myself. They also help me with paying my PA, I just have to take down my bank statements every few months and they handle everything from there.

Life now with a PA is so much better, because I don't feel rushed to do anything and we always get everything done when I need it done. With Jamie being my friend as well the relationship is more casual and not as "formal" as it was with Cordia, however I am still in charge.

If anyone is looking into getting a direct payment I would say go for it, there's nothing to lose. You can change your support whenever you want, and it just gives you more confidence in everyday life.



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In the period following the 1st edition of this book being published, sadly Glynis passed away

We would like to thank Glynis' husband Andrew, for graciously agreeing to the inclusion of "Glynis' story" in this reprint.

Like many disabled people Glynis spent her life battling to overcome physical and attitudinal barriers. As Glynis herself said

"The journey to where I am now has been a challenge but despite the problems my direct payment has given me control over the support I receive and the most important thing of all is that having the support of PAs means that Andrew is my husband not my carer."

We are delighted to be able to continue to feature her story.

# Glynis' Story

My name is Glynis and I live with my husband Andrew in the Baillieston area of Glasgow

I have severe disabilities and chronic health problems. For a number of years, until my health problems got worse, I worked for Glasgow City Council Social Work Services. I have always greatly valued my independence and being able to work was always very important to me. When I left school my ambition was to be a Speech Therapist and having gained enough qualifications I applied to Jordanhill College. At the interview I was asked "how would I be able to transfer patients to and from a ward" and "how would I be able to get children to respond to me?" (I am not very tall) I bet the other candidates weren't asked these questions! I was unsuccessful in gaining a college place.





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Having the  
support of PAs  
means that  
**Andrew is my  
husband, not  
my carer**  
”



In 1995 I had to go into hospital for an operation which unfortunately was not successful and what should have been a ten day stay ended up being seven months. It was during this time that Andrew asked me to marry him and at first I must admit I turned him down as I was very ill and disheartened at the time. I had two ambitions which at that time I was unable to contemplate achieving:

a) to get back to work and b) accepting Andrew's marriage proposal when I could walk down the aisle at my wedding. I was never able to get back to work but after two years of intensive physiotherapy I did walk down the aisle on the 21st June 1997!

Until I went into hospital for my operation most of my support was provided by my mum. However after the operation my mum could not do everything I needed as I required a great deal more support. At that time the option to have a direct payment was just being introduced. Fortunately the social worker who worked with me at that time was very knowledgeable and although I was a bit reticent at first, with her encouragement I decided to give direct payments a try.

I now manage five personal assistants (PAs) and they undertake a variety of tasks for me including personal

care, household tasks and shopping. They even help me to look after my dog Aiden and he is great pals with all my PAs! My point is that with direct payments you can write a job description to suit your needs, choose the people you want to employ, decide when you want to have them in your home and have tasks completed in the way you want them done.

Having a direct payment has its drawbacks. I would like to have more support to socialise, and to have the opportunity to get out to concerts or the cinema. Also I have to pay a contribution towards the cost of my support and our joint income is taken into consideration when Social Work Services decide the amount so it is pretty hefty and any increase in my direct payment is quickly followed by an increase in my contribution. I feel that this is an additional "tax" that disabled people are unfairly burdened with simply because we need support to do the things that other people take for granted.

The journey to where I am now has been a challenge but despite the problems my direct payment has given me control over the support I receive and the most important thing of all is that having the support of PAs means that Andrew is my husband, not my carer.



# Siobhan's Story

My name is Siobhan. I was born and brought up in Glasgow and lived with my family until 2007

My name is Siobhan. I was born and brought up in Glasgow and lived with my family until 2007 when, having decided that I wanted to be more independent, GCIL's Housing Service helped me to secure my own tenancy in Maryhill. I work for Glasgow City Council, Chief Executive Dept.

Until I moved out of my family home my dad had provided most of the support I needed. I decided that I would apply for a direct payment and GCIL got the ball rolling while I was preparing to move into my flat. I contacted Glasgow City Council Social Work Services and was allocated a social worker who took me through the whole process. This went well until the very end when the social worker had to tell me that there was no funding!

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Direct payments help me to continue to live an independent life

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During this time I received support from the Home Help service (as it was called at the time) but unfortunately the service was not very flexible and they were unable to offer a reliable service particularly in the mornings to help me to get up and ready for work. Fortunately funding became available and in 2008 I was awarded a direct payment which I have had ever since.

For the first year I purchased support services from a care agency which was ok and I employed my dad as a personal assistant (PA) for one hour each morning to help me to get ready for work. You may think that this is an unusual arrangement but I am used to my father supporting me, the agency could not identify anyone able to work for one hour at that time in the morning and the recently implemented Social Care (Self-directed Support) (Scotland) Act 2013 permits the employment of relatives in exceptional circumstances.

I got on really well with Marie, the support worker who the agency sent to support me, as she was very responsive to my needs and coincidentally she lived close by.

In fact we got on with each other so well that I eventually employed her as my PA! Marie assists with my personal care and household tasks. Generally I can get out and about on my own but I know she is available if on occasions I need assistance to go out somewhere. During the time I was supported by the Home Help service I can honestly say that the inconsistency of the morning service jeopardised my employment as I was too often late for work. Things are good now. My direct payment has been essential in enabling me to continue in employment and to keep “in the good books” with my employer!

I organise my support on a day to day basis and GCIL, as well as giving me lots of information and advice when I started, help me with the payroll. This means that they provide all the information I need to make sure that I pay my PAs the correct salary and the correct amount of tax. Seven years later I still know that I can lift the phone to GCIL when I need to and they will offer support.

Direct payments help me to continue to live an independent life.



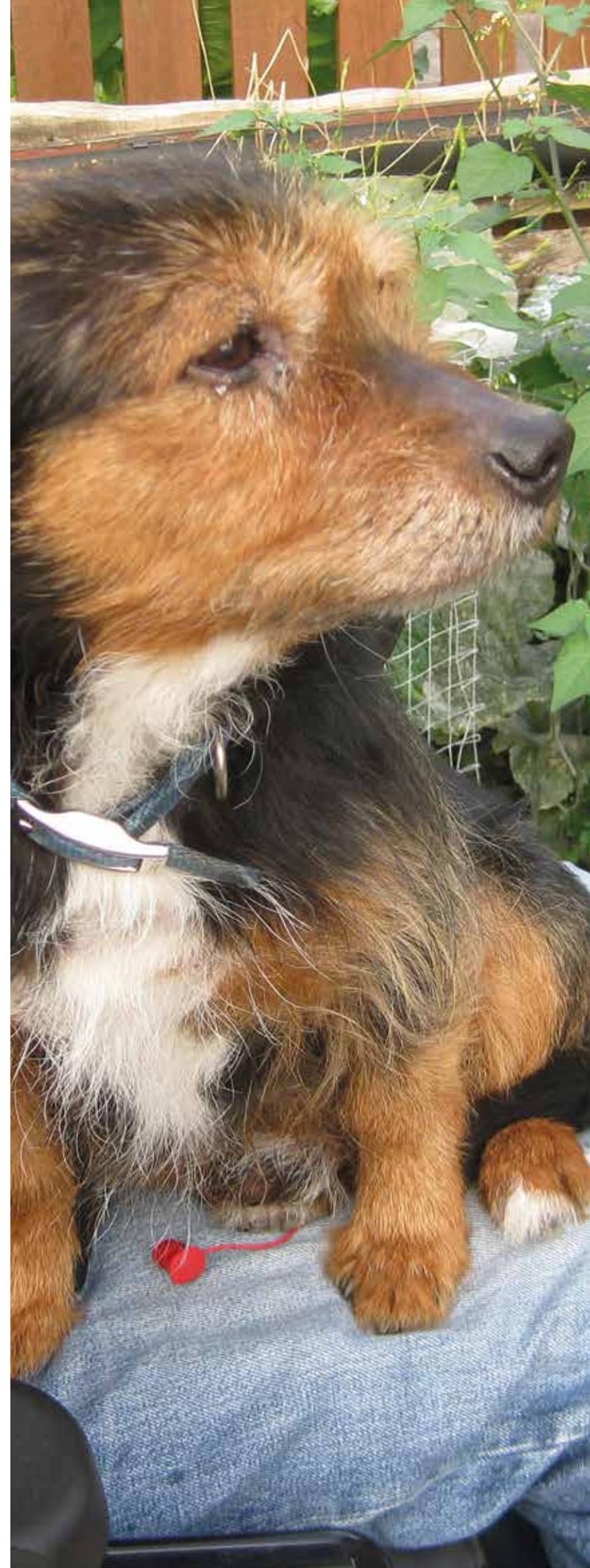


# Michael's Story

Directing  
my own  
support  
gives me  
a much  
better  
service

As Autumn approaches I am enjoying the "fruits of my labours." As you can see I am a bit of a gardener and I love good fresh food so my vegetable patch allows me to enjoy both! However without my direct payment this would be impossible.

When I think about it, good food has been a big part of my life. My dad ran a pub in Carntyne where I worked for a couple of years. After leaving the pub job I studied catering and successfully completed a Higher National Diploma. Unfortunately around that time I was diagnosed with Multiple Sclerosis so I had to change career and I started to work for Glasgow City Centre CCTV, where I remained for a number of years.



In 2000 I moved to a barrier free house where I still live. During the next few years I was supported by the council's Direct & Care Services (now Cordia) but the visits were very short and the times inflexible. A social worker visited me to talk about direct payments. She asked me what I wanted to do with my life and encouraged me to think about how I could widen my horizons. I was lucky as I found the process of applying for a direct payment to be very straightforward.

At this time, thanks to my direct payment, I became involved with the Glasgow Access Panel, Shopmobility and Consumer Focus, where I was a "mystery shopper," checking out accessibility, and service quality of different organisations.

I now use two agencies and I have four PAs. My PAs provide personal care,

help me to care for Bob my dog and, thanks to friends building the raised beds in the garden from left over decking planks, they help me to tend the garden. As well as the garden, having Bob has had a really positive affect on my life. He is great fun and as all pet lovers will understand, a great companion.

My family support me to go to the supermarket for ingredients, I choose the recipes and the agency staff I employ cook good fresh meals for me. In the past because DACS workers had such little time, I tended to end up with microwaved meals - ok once in a while but not all the time. I want to keep as healthy as I can for as long as possible and my lifestyle now supports that aim, thanks to direct payments. The agency staff are also good for providing emergency backup for sickness or holiday cover.

I do most of the administration required because I choose to do so. There is help if you want it and GCIL do help me to calculate what I should pay my PAs each month as well as making sure I pay the correct tax! There is one downside. I have to pay a contribution to my support which I don't mind doing but although the council's contribution to my direct payment does not go up (in fact it's been cut back recently along with my hours) my contribution has gone up. I think a fairer way of calculating this contribution, and informing people of this, is needed.

Direct payments gives me so much more choice and control. If, for example, I don't like the service that an agency is offering, I can simply go elsewhere. Directing my own support gives me a much better service.



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My name is Bryan, I had always wanted to live an independent life



**Bryan:** I had always wanted to live an independent life and 14 years ago I finally moved to a purpose built flat near the city centre. I need a lot of support and to begin with the Council's Direct and Care Service (now Cordia) provided care. It was ok but I had to fit in to their schedule, e.g. when I would have to go to bed, which did not always suit me. Also they only provided me with care in my home so I was never able to go out and I felt very lonely and isolated.

I was told that if I had a direct payment I could be more in control and I thought that was a great idea, if a bit scary! My mum agreed to help me to organise the direct payment and I decided to employ my own personal assistant (PA). Unfortunately the first PA did not work out too well and I lost a bit of confidence so I decided instead to buy the service I needed from a care agency. That's when I first met Mark.

# Bryan & Mark's Story

Bryan and my personal assistant Mark: [Our story](#)



My name is Mark, I am Bryan's PA

**Mark:** When I left school I had no idea I would end up working as a PA. As soon as I left school at 16 years I trained as a chef and worked for several years in hotel and restaurant kitchens around Glasgow. The work was hard and the hours long but I enjoyed it and had no thoughts of changing direction. Then my father-in-law became terminally ill. It was a difficult time for the whole family and the support workers he had during that time, I'm afraid to say, were not very skilled. Having seen what my father-in-law went through and although I had no caring experience, I just felt I could do better. I left my job and started with a care agency and that's when I first met Bryan.

**Bryan:** Mark and I hit it off right away. I have difficulties with speech but Mark never stops talking! He was great company and it gave me a real lift.

**Mark:** Working with Bryan was brilliant from day one, he has a real spark about him. However I didn't like working for the agency as they did not seem to treat staff and service users with the respect and dignity that they deserved, so after 8 months I reluctantly handed in my notice. I dreaded telling Bryan and his mum that I was leaving and we were all very upset. Although Bryan had a poor experience with his first PA, he took a leap of faith. He and his mum approached me and asked if I would consider being employed as Bryan's PA - well since then we've never looked back!

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**Bryan:** From never being out I am now never in! Since Mark became my PA I have joined a local garden group that looks after an allotment and I receive a share of the fresh produce. I attend social groups, go on regular trips and to rugby sevens which is my favourite sport. We went to the Commonwealth Games and as you can see I was recently involved in a bit of political campaigning. And, thanks to Mark's past experience as a chef my meals are pretty good too! I still have care agency support workers for some personal care and to cover for Mark's time off and this works well as a back up.

If things don't work out at first, don't give up – just go for it!

**Mark:** If you are thinking of applying to be a PA. Go on - try it!



“  
Don't give up  
just go for it  
”

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My name is John and I live in an adapted ground floor flat in the north of Glasgow

# John's Story

I am a great football fan and you may think this strange, because I live in Glasgow, but at the moment I am following St Johnstone! Ok this is because my nephew is currently a striker with the team and his father (my brother) and I travel to all his games. It's thanks to direct payments that I am able to do this and other activities in and around my local community.

My name is John and I live in an adapted ground floor flat in the north of Glasgow. I worked until March 2000 when I was the victim of a road traffic accident and ended up in a coma for seven weeks followed by a lengthy period of rehabilitation. I suffered severe injuries to my spine which has left me with long term pain and limited mobility. I now have to use a wheelchair if I am going out.



Prior to my accident I would say I was super fit. I played football and was on the go all the time. The period following my accident was very difficult. I took a lot of time to come to terms with the radical change to my life and admit I retreated into a very dark place. However there came a time when I had to decide whether to "sink or swim," I decided to "swim".

For the first 11 years I received support from Cordia (home care) plus support from my brothers which I was quite happy with. However I was confined to the house most of the time.



A social worker came out to assess my needs and actually asked me what I wanted to do. I loved sport and musical theatre but I had not seen a match or production since my accident. Following the assessment I was awarded a direct payment with a budget to cover both personal care and to help me get out to activities. However I did not have enough to continue to afford Cordia so I had to move to another care agency. Not long after this the care agency went bust but I got on well with the support worker from the agency so I employed her as a PA and my second



PA was recommended to me locally. Employing people directly was completely new to me but you learn and GCIL was a great support. Now I manage the PAs on a day to day basis and GCIL keeps me right with paying salaries and tax etc.

As I said before my brother now drives us round the country to watch the football. I cover the cost of petrol from my direct payment and my brother provides my support for the day. When I go to the theatre I pay for my ticket myself and pay for the person supporting me from my direct payment. Everyone wins

- I get to see a show which would be impossible without help and my companion gets to see a free show. Because I have control of my budget I can plan in advance where I want to go to and work out what I can afford. Having a direct payment gives me tremendous freedom but you have to use it wisely and be responsible.

I now have a very positive outlook on life. My brothers are very supportive, I am immensely proud of my four daughters' achievements and the support they give me and I have good friends. Life could be a lot worse!!

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# B's Story



My wife and I are involved in a major project to adapt our family home

As I prepare this story, my wife and I are involved in a major project to adapt our family home to increase our sons' independence.

Our two sons J and D have severe learning disabilities, but the changes we are making to the house should allow them to develop as individuals with the necessary support.

We are originally from Ayrshire where our sons received support from a local care organisation. While we appreciated this support we were given little choice, and the quality of the organisation's support was unfortunately rather variable. We are a small family with little informal support and therefore at times we felt very isolated. However, thanks to good support from Ayrshire Social Work Services we were one of the first families in the area to receive a direct payment.

“  
Direct payments allow our sons the freedom to be individuals...  
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In 2002 when J and D were in their teens we moved to Glasgow and the boys settled into their new school which they loved. We received a similar level of direct payments for the boys but this time instead of using an organisation we set out to employ our own personal assistants to support the boys.

Since 2002 we have had wonderful PAs from a wide variety of backgrounds including law, the arts, music, creative writing and even a trained chef! We even "poached" one of the staff from the boys' after-school club for J, but in our defence this was with the full agreement of the Head Teacher who was responsible for the club! Everyone recognised that this particular member of staff had a great relationship with J. We employed other people with club



experience as extra support and they are able to continue both jobs as the hours are compatible. It's great for the PAs too. Our PA with the art background is about to embark on a community nursing course and we would like to think that his experience with J inspired him to further his career in health and social care.

The point I would like to make is that we chose PAs not because they have "care experience" but because they have the skills, personality and flexibility to support and encourage our sons to try out a range of activities and enjoy the positive experiences available to any young person in the local community. Of course there are caring tasks too but as their parents we can train, or arrange training, for the PAs to carry out the caring tasks required.

I manage the direct payment paperwork, organise PA rotas and GCIL arranges the payroll for the PAs. I know that GCIL is there if I need them and they have been a fantastic support.

These days J is supported by three PAs and he is out and about with them all the time. D attends a day centre and he has one PA who works with him in the evenings. Both have even been away for weekends supported by the PAs.

Life is still a challenge but we feel well supported. Our home conversion should give our sons greater independence and a sense of ownership. We also hope it will secure the long-term future for both of them in their own home. We are feeling very positive.

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...and allow  
us to be  
'mum and  
dad' not just  
'carers'

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# Nonny's Story

**My name is Nonny. I was born and raised in Nigeria and came to Scotland when I was 17yrs**

My name is Nonny. I was born and raised in Nigeria and came to Scotland when I was 17yrs. I lived with my grandparents for a short period then moved into a care home on a temporary basis until a flat was identified. I stayed in the home for a month followed by a hostel for 9 months and when I was 18yrs I moved into my own flat.

To begin with I did not have much support as I was only allocated about 15-20 minutes a day from Cordia (home care service). Sometimes I didn't even get that time and this was stressful as I wasn't always fully ready when the support worker left. Also I only had the support Monday to Friday so basically I had to depend on myself at weekends which was very difficult.



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Direct  
payments  
are easy to  
organise if you  
have the **right**  
support  
”

I wanted to be able to get out and about more. I love sport and keeping fit and I wanted to be able to get out and do the things I enjoy. I met with a social worker to discuss direct payments and GCIL helped me fill out the forms as I find filling out forms hard and confusing to understand. Happily I was successful and since receiving a direct payment my life has changed for the better and I have the support that is needed on a daily basis.

I had the choice of employing support workers from an agency or employing my own personal assistant. I like to use an agency because they help me if anything goes wrong and they also help me to manage my support workers. The first support worker they provided was brilliant and she is still working with me 13 years later! She knows me really well and has also got to know my family too. It has made life easier and less stressful. Once I was sent a worker that I just didn't gel with and on that occasion the agency replaced the worker. I am not suggesting there was anything wrong with her caring skills but when you have someone in your home you want to feel comfortable with that person so don't be afraid to raise any concerns you might have with the agency manager.

I have a regular number of hours per week plus the good thing is I can bank hours that I sometimes don't need to use. So if I want to do something special at the end of the month like go to the cinema or have extra support to go and see my friends, I have some hours in reserve to allow me to do that. I usually plan what I want to do and my support worker helps me to get organised for the following week.

Every 3 months I have to provide bank statements for Glasgow City Council and GCIL help with this as well as paying the agency. GCIL also support me to sort out any minor problems with the agency which fortunately are rare.

Life is a lot more organised and I'm a lot less stressed now. It is all down to having more time and I'm not rushed anymore. I also have more control. I get more freedom to plan things and do things. I don't have to ask or depend on neighbours to do things for me. As you can see from the photographs I spend a fair bit of time at my local sports centre doing all kinds of different sports and I also enjoy the occasional coffee!

Direct payments are easy to organise if you have the right support and GCIL gives me all the support I need.

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My Name  
is Joan, I  
have Spinal  
Muscular  
Atrophy.  
I am 48  
yrs young  
and work  
for The  
Wheatley  
Group

# Joan's Story



It was almost Christmas 2009 and I was enjoying "faffing" (as my friend Katrina calls it) in my new house. Doing what I wanted when I wanted...great! I couldn't believe that it had really happened and looking back how I feel I have changed...

I have Spinal Muscular Atrophy (muscle wasting condition), am 48yrs young and work for The Wheatley Group. I only left my family home 5 years ago! Yes, ridiculous but I enjoyed living with my parents and although many of my friends had been living independently for years I never really wanted to do it. Looking back I was probably worried too much about not feeling comfortable with people other than my mum assisting me.

In 2008 a flat became vacant near my parents and I thought, "I'm not going to get anything more suitable so let's have a look." I remember the day I went to see it I was horrified as it was in a filthy state but I could see the potential and it could be adapted to suit my needs.

The next stage was to apply to Social Work Services for a direct payment so that I could not just have support but be able to have choice and control over the support I received. I did have a lot of problems getting direct payments and that did make me a bit angry but my wonderful friends supported me to fight for what I felt I was entitled to and Glasgow Centre for Inclusive Living were fantastic - a wealth of knowledge.

My Occupational Therapist helped to get the adaptations I required and my housing association was great. As I worked for City Building (the contractor for the housing association) at the time, I was able to work with them to get everything just right!

I've chosen to employ personal assistants rather than carers from an agency and I have been extremely lucky having found great PAs.

I prepared my own advert, a job description to suit my needs, did my own interviewing with GCIL's help, and I now manage my own care package, pay my staff and it all works out really well.

Employing PAs means that I can make clear to them at the very start how I wanted to live my life. I have control over tasks my staff carry out and the hours they work as long as I keep within my budget. I don't have lots of different carers who I don't know suddenly appearing at my door to provide me with e.g. personal care!

I could not continue to work if I did not have PAs helping me in the morning and evening. Going out to work and being financially independent is very important to me.

I had a great life living with my parents but if I am honest my one regret is that I did not start living the life I have now long before I did.

What would I say to others thinking about going through Self-directed Support? Talk to people about their experiences and think about what you want from life. Direct payments gives you the freedom and choice to live the way you want.



“Direct payments gives you the freedom and choice to live the way you want“

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# Allan's Story



My name is  
Allan and I  
live in the  
Royston  
area of  
Glasgow

**Allan:** My name is Allan and I live in the Royston area of Glasgow. I enjoy watching football, keeping fit, getting out and about to socialise and using the computer to communicate with friends and family.

Originally I was supported by an agency but I didn't like that very much. I felt that they were in charge and I didn't have much say. They were always sending different workers and I found it difficult and tiring to explain my support needs over and over again. Also at that time I only got support during the week and at the weekends I had to try to get any help I could from other people.

When it was agreed that I could have a direct payment, my social worker helped me get in touch with GCIL and I came to meet an Inclusive Living Adviser. I wanted to employ PAs but also to have some hours from an agency and they helped me to get that organised. Now they help me with paying everyone that I have employed and if I have any problems or questions I just give them a call.

I now have both a PA called Jackie and staff from an agency and I split the hours I need between the two. I also use the agency for cover when Jackie is on holiday or off sick.

My PA Jackie provides most of my support because she knows me so well. She helps me get up, get washed, dressed and she also prepares meals. Jackie also helps me around the house as well as with cooking, cleaning, washing and makes sure I have food in the house. As she is able to drive she can take me shopping and to medical appointments etc. Because Jackie is so aware of my support needs, before she leaves the house she leaves a "to do" list, of what I need done, on the fridge for the agency staff.

**Jackie:** It is important for Allan to have support workers who can drive as Allan has a Motability car and likes to get out into the community. In the past some of the agency workers sent couldn't drive which caused difficulties when they needed to take Allan places but fortunately his current agency is working well. However some agency workers don't realise how long it takes for Allan to do things and he can get easily frustrated with them. It is important that those of us working for him communicate with each other.

**Allan:** Life has its ups and downs but it's not too bad. I just take it from week to week although it is better now than what it was. I get more hours now but not as many as I would like.

**Jackie:** Being a PA I get a lot of job satisfaction from my work. You get to know the person and you can have a friendly relationship though I am still aware of the fact that I'm employed by the person.

**Allan:** I would recommend direct payments because you'll be in charge. It's a lot better than any service the council provided for me. Although for me I would like to have more hours.



“  
I would  
recommend  
direct  
payments  
because  
you'll be in  
charge  
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*Me,  
Robert  
on our  
Wedding  
Day  
1969*

# Irene's Story

Robert and I were both great fans of Jiving and spent a good part of our youth, with fellow dance enthusiasts, in and around the dance halls of Glasgow. We are East End born and bred and we have always lived in different parts of the East End. Robert was a driver for Glasgow City Council Education Services for many years, eventually retiring about 6 years ago at the age of 65.

Unfortunately shortly after his retirement Robert suffered two strokes and this has led to long term disability. After he came home from hospital, Social Work Services came out and assessed Robert's needs. They then provided support from Cordia (home care). Things started well but while we received a good service from individual workers I felt that the hours weren't flexible enough, that sometimes the workers were in a bit of a hurry to get to the next service user and we often had different workers coming in who did not know Robert or me and it became wearing having to explain Robert's needs over and over again.

**My name  
is Irene, my  
husband  
Robert and  
I met in the  
Barrowland  
ballroom  
more than  
45 years  
ago**



I decided that we should try direct payments and it was agreed that I would manage the direct payment on Robert's behalf. I decided to use two local care agencies. One provides the daytime support and the other



*me, Dad, Suzanne & young Harrison*

provides support in the evenings. The agencies worked with me to plan the hours which suit Robert's needs and although sometimes we do still have some new workers to cover holidays etc., the service is much more consistent and relationships between Robert and the support workers are good. Robert has support each morning and evening. He attends a day centre two days a week and the support workers take him out 2-3 times a week using the local "Dial a Bus" service to activities, shops and the bookies where he still enjoys a flutter on the horses!



Although the direct payment is provided to meet Robert's needs it also indirectly helps me out too. As Robert's only informal carer it can be tiring and stressful. The support service that we have been able to purchase for Robert allows me some time to myself knowing that he is safe, happy and well cared for.

I attend a local carers support group run by one of the agencies that supports Robert, also a group run by a Glasgow based mental health support organisation and I go to keep fit. I have just started to attend an introduction to technology course called "DigiKnow" at GCIL so I hope to soon be doing things like emailing and surfing the net.

I can honestly say that these supports have saved my life. I have enjoyed getting involved in a variety of activities and relaxation sessions, have made friends with other people who understand and even as part of a group activity made a book of my life with photos and reminiscences. Took me back to those Barrowland days!

Life is not perfect but both Robert and I feel supported. GCIL has provided great advice and I have recently started to use their bill paying service which has taken a weight off my shoulders.

If you are thinking of managing a direct payment for someone you care for I would say "Go for it."

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I might be  
severely  
disabled  
but I have a  
good brain!

# Jean & June's Story

Jean and my personal assistant

June: Our story

**Jean:** When I was young I never dreamed I would get to where I am now - controlling my own support and employing my own staff.

Thinking about this story takes me back to my childhood. My mum and dad had to do everything for me but as I grew up and my mother became ill they couldn't manage any longer so I was placed in care when I was 10 years old. After some years my brother took me home again and was my main carer for many years. During that time I went to a day centre and because I received money from the Independent Living Fund my brother employed carers to help out. That's when I first met June.



My brother died a few years ago which was very sad but it was also a real turning point for me. I was determined to remain in my own home and when a social worker visited to discuss my needs, she suggested that I apply for a direct payment. She explained to me that having a direct payment would allow me to control and organise my own support. I thought, why not? I might be severely disabled but I have a good brain!

Once I received the direct payment I never looked back. When June worked with me we had got on really well so I employed her as my first personal assistant. I now have five PAs as I need 24/7 support.

**June:** My previous employment could not have been more different. I travelled round the country collecting the takings from fruit machines in pubs and clubs. I enjoyed the job and the hours fitted well round my childcare arrangements but after a while I started looking for a change. A friend who was working with Jean was leaving so I thought I would give it a try and applied to take her place - that was 14 years ago!

I enjoy the flexibility that the job offers but the most rewarding aspect is seeing that Jean is happy and thriving and that I and the other PAs have contributed to that.



**Jean:** I now go to a day centre once a week which I enjoy and my PAs help me with personal care, meals, housework and shopping. Before having the PAs I rarely got out but now I go to the cinema, into town shopping and go regular trips to places like Loch Lomond and down to the Ayrshire coast. My PAs have travel and cinema companion cards so I don't have to pay any additional costs. Now that I am a bit older I may have to change day centre which I am a bit anxious about but one of my PAs will take me to see any new day centre before I make a decision.

June helps me to organise the rotas and assign tasks for the other PAs but I remain in charge! GCIL gave me lots of help, particularly at the beginning. Now they help with paying the PAs and they are at the end of the phone to offer help when needed.

Life is so much better now because I am in control.

**June:** Being a PA is a hugely rewarding job but you have to remember that it is the person who employs you who is in control and whose wishes must be respected.

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My name is  
Tommy.  
I am  
enjoying  
the benefits  
and  
freedom  
that Self-  
directed  
Support  
has  
brought  
me

# Tommy's Story



My name is Tommy and I am in my early 60's. I spent my early life in Johnstone near Glasgow where I lived with my mother, father, brothers and sisters although sadly my father died when I was very young. I have a mild learning disability and physical impairment and I needed quite a bit of support because of my epilepsy, which at the time was very active. I had some help from my sister who lived nearby, but when my mother's health started to fail in 1982, I moved into a residential home in Erskine. I lived there for 10 years before moving to my own supported tenancy, in one of Margaret Blackwood's developments in Glasgow, where I have lived ever since.

I left school at 15. After a short spell in a gardening project in Hillington I started work in a sheltered work centre where I learned to make bags and put pins into barrels used in the making of blinds and curtain fittings. I remained there for 32 years until the centre closed in 1996.

“

Social Work then supported me with day opportunities and some housework and this worked well for a few years but the service then changed. I had fewer hours of support and I also had to share one workers' time with other service users. I was doing activities that I didn't want to do with people that I sometimes didn't even know and this was not my idea of being independent. This was a real low spot in my life. I felt let down because I was not getting the services I had been promised and I was being forced back into a day centre although I had "outgrown" that.

Around this time I heard about Self-directed Support and direct payments and I thought that this could be what I was looking for. With help from a very supportive social worker I was given a direct payment to employ my own staff.

Self-directed Support has changed my life. I can choose when I want to do things, for example going to country and western evenings, which I really enjoy. I'm more confident now.

I go out on Friday and Saturday nights, something I had never done in my life and I have met other folk who I would never have met otherwise.

GCIL helps me to manage my direct payment, and recruit and pay my personal assistants. I've learned how to become an employer and I have developed a good working relationship with my PAs. I've taken control of my paperwork and banking matters. Before direct payments I felt I had no control but now I have control and a feeling of contentment. I also know if I make a mistake, it's on my head!

My life is now on the right track and I am enjoying the benefits and freedom that Self-directed Support has brought me.



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## Self-directed support has changed my life





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