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# Self-directed Support in Scotland

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Capturing the experience of people  
living with dementia



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The Life Changes Trust was established by the Big Lottery Fund with a National Lottery grant of £50 million to drive transformational improvements in the quality of life, well-being, inclusion and empowerment of people affected by dementia and young people with experience of being in care.



# 1. Social care in Scotland

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Social care provides care and support to people who need help to live their lives.

*Adult social care describes the activities, services and relationships that help people live independent, healthy, active and inclusive lives. It covers a great variety of services, delivered by many different providers, in a selection of settings. For example, adult social care can include domiciliary (home) care, residential care, nursing care, day care opportunities, short respite breaks and the provision of equipment.<sup>1</sup>*

Across the UK social care has a strong presence in many people's lives.

An independent YouGov poll indicates that 1 in 3 people either receive or are in touch with social care services.<sup>2</sup>

In 2017 Scottish Government figures show that 212,220 people in Scotland were using social care services, provided or funded by local government.<sup>3</sup>

It is a large sector underpinned by huge public sector resources but is one that does not work well for many people.

*We regard the current situation - rising demand that is fast outstripping investment, coupled with an approach providing little more than life and limb support to dwindling numbers of people - to be increasingly out of step with modern life and expectations. As a consequence, without action, families will be increasingly relied on to fill the gap...<sup>4</sup>*

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1 <https://www.bma.org.uk/collective-voice/policy-and-research/nhs-structure-and-delivery/primary-and-community-care/social-care>

2 [Distinctive, valued, personal. Why social care matters: the next 5 years – ADASS April 2015](#)

3 <https://www.gov.scot/Publications/2017/12/3849/349112>

4 <http://new2.ilis.co.uk/uploads/documents/Shared%20Ambition%20for%20social%20care%20-%20final.pdf>

## 2. Personalisation and Self-directed Support (SDS)

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In an attempt to address the challenges in social care delivery and dissatisfaction with traditional forms of care, policy on social care has shifted. The focus is now on more personalised approaches able to support the person across the whole of their life, not just in a narrow care context.

A key strand of this policy shift is self-directed support – a different way to think about state-funded care. It means that people gain control of the money the council would have spent on their care.

*The Scottish Government believes everyone should be in control of their life. Some people need support to lead an independent life and advocacy to be empowered to make important decisions about their life.*

*In order to achieve this the Scottish Government introduced The Social Care (Self-directed Support) (Scotland) Act 2013. The Act came into force on 01 April 2014 and places a duty on local authority social work departments to offer people who are eligible for social care a range of choices over how they receive their social care and support.*

*Self-directed Support allows people, their carers and their families to make informed choices on what their support looks like and how it is delivered, making it possible to meet agreed personal outcomes.*

*Having more choice and control is empowering. We should all be equal partners in making decisions that affect us. This leads to more of us being confident and independent and achieving our aspirations for a happier, healthier and more fulfilled life.<sup>5</sup>*

In theory people can use the money to buy the kind of help they want rather than having to fit into standard services. The result should be care and support delivered in ways that work for people.

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<sup>5</sup> Self Directed Support Scotland <http://www.selfdirectedsupportscotland.org.uk/self-directed-support>



*Self-directed support, alongside many other policies, is intended to support, promote and protect the human rights and independent living of care and support users in Scotland. It aims to ensure that care and support is delivered in a way that supports choice and control over one's own life and which respects the person's right to participate in society.<sup>6</sup>*

In Scotland there are 4 ways for people to direct their own support:

**Option 1** - a direct payment, which is a payment to a person or third party to purchase their own support

**Option 2** - the person directs the available support

**Option 3** - the local council arranges the support

**Option 4** - a mix of the above<sup>7</sup>

In 2016/17 Scottish Government figures showed that 70% of people using social care services had been given a choice of their support and services. This is recorded as 70% of people using self-directed support for the purposes of Government statistics. Figures show that 83% of people making a choice chose option 3, services arranged by their local council, with only 17% electing to take full control of their services and supports. 90% of people over the age of 65 chose option 3 with only 10% of older people electing to take full control of their services and supports.<sup>8</sup>

In 2017 Audit Scotland undertook a review of SDS in Scotland and determined that, while it was having a positive impact on the lives of many people, there is still work to do.

*Our evidence shows many examples of positive progress in implementing SDS. But there is no evidence that authorities have yet made the transformation required to fully implement the SDS strategy. Most people rate their social care services highly and there are many examples of people being supported in new and effective ways through SDS, but not everyone is getting the choice and control envisaged in the SDS strategy.<sup>9</sup>*

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6 Self-directed Support: Statement of Intent - Statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013

7 <http://www.careinfoscotland.scot/topics/how-to-get-care-services/self-directed-support/options-for-self-directed-support/>

8 Extrapolated from: <https://beta.gov.scot/publications/self-directed-support-scotland-2016-17/>

9 [http://www.audit-scotland.gov.uk/uploads/docs/report/2017/nr\\_170824\\_self\\_directed\\_support.pdf](http://www.audit-scotland.gov.uk/uploads/docs/report/2017/nr_170824_self_directed_support.pdf)

Concerns about the implementation of SDS were also reiterated by the Public Audit and Post-legislative Scrutiny Committee to the Cabinet Secretary for Health and Sport in February 2018.

*We heard stakeholders are generally positive about the intentions of the 2013 Act but there are significant concerns about the slow progress of implementing the SDS strategy.*

*...seven years into a ten-year strategy, of the 208,000 adults receiving non-residential care in Scotland only 53,000 (27%) have made an informed choice regarding their services and support.<sup>10</sup>*

### 3. Dementia

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Dementia is an umbrella term for many different illnesses which can affect people of any age.

*The word ‘dementia’ describes the collection of signs that a person’s brain has permanently stopped working as well as it used to. It is ‘dementia’ only if these signs continue to get worse, with a permanent deterioration over time. Over 100 diseases can cause changes in the brain that give rise to these symptoms. The most common is Alzheimer’s disease followed by vascular dementia.<sup>11</sup>*

The way the illness affects the person depends very much on the type of dementia they have and the part of their brain that is damaged.

*Currently there are 90,000 people living in Scotland with dementia. By 2020 it is estimated that there will be around 20,000 new cases diagnosed each year.<sup>12</sup>*

So more than 1.5% of the population of Scotland are living with dementia and this number is increasing year on year.

In 2017 Alzheimer Scotland, the Convention of Scottish Local Authorities (COSLA) and the Scottish Government published the third National Dementia Strategy for Scotland. In it they state the key outcomes they want to see as:

- *more people have increased say and control over their dementia diagnosis and are diagnosed early enough that they can take as full a part as possible in their own care planning*

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10 [http://www.parliament.scot/S5\\_Public\\_Audit/General%20Documents/20180221\\_Letter\\_to\\_Cabinet\\_Secretary\\_-\\_SDS.pdf](http://www.parliament.scot/S5_Public_Audit/General%20Documents/20180221_Letter_to_Cabinet_Secretary_-_SDS.pdf)

11 <https://www.lifechangestrust.org.uk/people-affected-by-dementia/scope-challenge>

12 [https://www.alzscot.org/assets/0002/6035/Third\\_Dementia\\_Strategy.pdf](https://www.alzscot.org/assets/0002/6035/Third_Dementia_Strategy.pdf)



- *more people get earlier access to good quality, person-centred post diagnostic support in a way that meets their needs and circumstances*
- *more people with dementia are enabled to live well and safely at home or in a homely setting for as long as they and their family wish*
- *more people get timely access to good quality palliative and end of life care*
- *during the process of diagnosis and through all parts of the care journey, the critical input of family carers is encouraged and facilitated, and carers' own needs are recognised and addressed*
- *people with dementia's right to good quality, dignified, safe and therapeutic treatment, care and support is recognised and facilitated equally in all care settings – at home, in care homes or in acute or specialist NHS facilities*
- *there are more dementia-friendly and dementia-enabled communities, organisations, institutions and initiatives*

There is a focus on real choice and personalised services and supports as means of underpinning activity aimed at achieving these outcomes.

Scottish Government figures for 2016/17 show that less than 10% people with a primary diagnosis of dementia are using self-directed support.<sup>13</sup> Given the dementia strategy, anticipated outcomes, and a commitment to personalised approaches to achieve these outcomes, this figure would appear to be low.

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<sup>13</sup> <https://www.alliance-scotland.org.uk/wp-content/uploads/2018/08/SDS-Data-Under-Development-2016-17.pdf>

## 4. The project

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The Life Changes Trust is a Scottish charity that wants to improve the lives of people affected by dementia. The Trust is interested in self-directed support and how it currently works in practice for people and their families.

The Life Changes Trust asked social enterprise Community Catalysts to talk to and learn from people and their families who have experience of self-directed support. Community Catalysts and the Life Changes Trust hope that the information gained will help improve understanding of how self-directed support works in Scotland for people living with dementia.

People living with dementia and their carers who had experience of SDS were invited to make contact using the following questions:

- ✓ **Are you living with dementia or care for someone who is?**
- ✓ **Do you have experience of self-directed support?**
- ✓ **Would you be willing to share your experiences – face to face or by completing a short questionnaire?**

In depth interviews with 5 people were undertaken and their experiences of SDS recorded. These (stories 1 to 5) form the backbone of this report. In addition an electronic survey was developed, promoted and used to capture the experiences of 12 people who wanted to contribute in a less intensive way.

The 5 people whose detailed stories were captured lived in 5 different local authority areas. Overall, contributions were made by people from 9 different areas including North Lanarkshire, Glasgow, Perth and Kinross, East Lothian, East Renfrewshire, South Ayrshire, Aberdeenshire, Argyll and Bute and Inverclyde.

All the people we spoke to or heard from, who had experience of SDS, had used option 1 or option 2 to direct their own support.





## 5. Lessons learned from people

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### 5.1 Dementia has a huge impact on people and their families

People spoke about the impact of dementia on the person with the diagnosis and the people who care for them.

*'It has a huge impact on our lives. Exhaustion, frustration and watching the person disappear.'*

*'Her behaviours have changed. She is very angry most of the time, cruel and verbally abusive to those closest to her. In her more lucid moments she is frightened about what is happening to her.'*

#### **Post-diagnostic support is not always available**

The Scottish Government Dementia Strategy<sup>14</sup> makes a commitment that 'People newly diagnosed with dementia will be offered a minimum of one year post-diagnostic support, coordinated by a named Link Worker'. However, this does not always translate into practice.

*'The ideas and plans are all good but a lot of people out there are not getting post-diagnostic support.'*

### 5.2 When it works, SDS can have a hugely positive impact on people's lives

Most of the people we met were clear that SDS can have a hugely positive impact on the lives of people living with dementia and their carers.

*'Things could change on a day to day basis, the direct payment was so flexible, it just allowed us to react to what Mum needed. I don't think any of the other SDS options would have worked in the same way.'*

*'I have been able to have some time free to do things.'*

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14 <https://www.gov.scot/About/Performance/scotPerforms/NHSScotlandperformance/Dementia-LDP>

### 5.3 The journey to SDS is very challenging

#### You need a dementia diagnosis to unlock help

Having a dementia diagnosis is key to unlocking social care resources and services, including SDS. Dementia is complex and often misdiagnosed and/or misunderstood. This is particularly the case for younger people with dementia and those who have a rare condition.

#### Information is not readily available

People told us how they found out about SDS for the first time. Different people got information from different sources. People talked about third sector organisations, local carer groups, Community Nurses and Social Workers as sources of information.

*'If you don't know about SDS the council doesn't tell you.'*

*'It is too complicated to understand....'*

#### Barriers are put up

More than one person we met found it very hard to get SDS with obstacles and challenges at every turn. One family talked about active resistance from their local council who did not seem to want them to go down an SDS route. This person thinks that SDS is not encouraged for older people in her area.

*'If I hadn't been persistent with them I wouldn't have got anywhere with it. I faced resistance all the way.'*

*'It was very positive but the process to get there was very complicated and difficult.'*

### 5.4 Many people experience a significant gap between the rhetoric around SDS and the reality

#### There is too much focus on personal care

Two of the people we spoke to found that all discussions about the help they needed and resources available were linked to help with personal care.

*'They did not have a focus on her living a full and active life.'*

In both instances they did not need help with personal care, they needed help with other aspects of their lives.



*'In Scotland over 65s get free personal care and somehow the SDS budget and the personal care budget are in the same pot. I was doing the personal care and didn't need help with that. We needed someone to be with him when I was out of the house, to manage the risks and keep him well.'*

### **SDS is not easy**

Most of the people we heard from were clear that managing a Direct Payment or personal budget is a real challenge.

*'We eventually had to give up due to exhaustion from caring. The overall paperwork for the SDS became too stressful.'*

*'There was an expectation that carers know about employment law systems. I did not know how to do annual leave etc and this gave a lot of stress to an already very stressful situation as a carer of someone with advanced dementia.'*

### **People need strong personal resources to make it happen**

All the people we spoke to were strong and inspirational people, many with supportive families and an excellent knowledge of what is possible for people with dementia. Without these combined factors the lives of people with dementia would probably have been very different and the positive impact of SDS less likely to be realised.

*'You need to know what is possible and be capable and willing to fight for it.'*

*'It wasn't looking after my husband that stressed me out, it was fighting the system.'*

*'They deliberately put barriers up.'*

### **Strong networks can help to navigate the system**

One of the people we met was clear that they are not afraid to ask for help from some of the excellent agencies which exist for that purpose. They have had a lot of help from different agencies to understand their rights and to navigate the health and social systems and SDS in particular. This includes Minority Ethnic Carers of Older People Project (MECOPP), an organisation which offers legal advice on SDS issues to people and their families, the local Centre for Independent Living (CIL), Alzheimer Scotland, SDS Scotland and a specialist adviser in Glasgow. This person and others were clear that without this supportive network, they would not have been able to get the flexible help that was needed in ways that worked for them.

*'On my own I just can't break through, but with help from my network...'*

*'We got all our information about SDS, personalised approaches and choice from an excellent third sector support organisation.'*

## **5.5 People identified some specific barriers to making SDS work for them**

### **There are different challenges for younger people**

One person we heard about was 50 when he experienced his first symptoms and only 56 when he died. This had an impact on his diagnosis, assessment, support package and the experience of the family as a whole. It also had an impact on the family finances.

*'They didn't know what to do with us.'*

### **SDS needs to be available earlier**

One of the people we spoke to wanted their loved one to remain as independent as possible for as long as possible, living his life his way. For people with dementia, Council assessment and funding is linked to crisis and not to early intervention and prevention.

*'The time for SDS is when the person could have a good independent life.'*

*'We waited months for a Social Worker and by that time it was too late.'*

*'By the time he got it, it was the wrong time for him. It is really sad that he didn't get it early enough. He could have had freedom to be himself.'*

### **Local help with SDS does not always have a dementia focus**

One of the couples we heard about had a local SDS forum in their area. This provided some help which was welcomed but had a much stronger focus on younger disabled people than on dementia.

*'I am not sure they see the needs of people with dementia. The focus is more on the young people.'*

### **Budgets may not be enough to help someone live a full and active life**

The personal budget offered to all the people we met was enough to meet basic personal care needs but nothing more. Everyone we spoke to needed to add money to the budget. Not everyone would be able to do that.



*'We had to top it up...the alternative would have been a strait jacket.'*

### **Rights and privileges mean little without proper funding**

Two of the people we met had strong views that the current economic climate placed real challenges on health and social care in Scotland and SDS in particular.

*'There is no funding because the economy is flat-lining and there is no real economic stimulus. Local Authorities cannot deliver on their obligations and many are teetering on the edge of bankruptcy.'*

*'SDS in the current economy isn't going to work.'*

### **Dementia is not seen as a terminal illness**

Dementia is either seen as part of ageing or as mental illness with little recognition of the fact that it is life limiting. End of life care for people with dementia can be poor.

*'This is not about personal care – it is about supporting someone to live well with a terminal illness.'*

*'I was helping him get a good life while also dealing with grief.'*

*'He wanted to die at home.'*

*'They have to improve end of life care for people with dementia.'*

### **Challenges in the homecare sector impact on people using SDS**

Several of the people we met used traditional homecare services initially but problems with reliability meant they decided to employ their own staff to give the freedom to customise the care.

*'We initially used it (the SDS budget) to get a care company to provide support but had immense problems. We then employed private carers.'*

## **5.6 Some ideas about how to make it work better**

### **Taking a lead can help carers avoid frustration**

One of the people we met was clear that relying on the state will always bring challenges and frustrations.

*'No-one will care more than you do.'*

*'Carers need to identify the needs of the person they care for. Be prepared to think laterally to find solutions. It means not giving up. And if you can, don't just rely on the state. It cannot and will not come to the rescue. Identify what you can do (for example can you fit grab rails instead of waiting months?) – then get on with it. The more you can do for yourself, the less frustrated you will be.'*

### **Try to see things from the professional's perspective and work with them to make things happen**

Understanding the pressures that professionals face and the context in which they have to operate was seen as key for one of the people we met.

*'We need to understand what their problem is and what they need from us. Then if we deliver that to them and give them the ammunition they need to take on the challenge we will all get more done. It can lead to positive partnerships and real good will.'*

## **5.7 It is a postcode lottery**

One of the people we met was clear that their poor experience of SDS has some link to the council area in which they live.

*'It is a postcode lottery. I know someone in another area who has a different and much better SDS story.'*



## 6. Recommendations for strategic decision makers

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### National

- Acknowledge the challenges faced by people with dementia and their carers in accessing and managing SDS.
- Simplify SDS information and processes to ensure they can be easily understood and navigated by people, carers and supporting professionals.
- Ensure SDS strategies specifically address the issues of people living with dementia and their carers.
- Tackle the post code lottery to ensure that people wherever they live have a positive experience of SDS.
- Specifically include SDS in future iterations of the National Dementia Strategy for Scotland.
- Work with people living with dementia and their carers to co-produce guidance for local government and Direct Payment advice organisations that highlights challenges and barriers and shares examples of good practice in overcoming these.
- Use existing work to develop peer networks and peer support to capture and share positive SDS stories and ideas from people with SDS experience.
- Work with NHS Scotland and Healthcare Improvement Scotland to ensure that dementia is better integrated into guidelines relating to palliative care in Scotland.<sup>15</sup>

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<sup>15</sup> <http://www.palliativecareguidelines.scot.nhs.uk/>

## **Local and regional**

- Offer assessment and low-level support to people with dementia at an early stage. Promote the use of small personal budgets to keep people and their carers active and independent. See SDS as a way to avoid or delay crisis.
- Explore the potential for community led marketplace development, nurturing the development of smaller, local, person centred services and supports. This has the potential to fill the gap between large traditional care agencies and people employing their own staff, making SDS more attractive and accessible.
- Work with people living with dementia and their carers to co-produce engaging, accessible information for people that is specific to dementia, shares tips and shows what is possible.
- Link the development of post-diagnostic support, contained in the Dementia Strategy, to strong information and advice on SDS.
- Ensure GPs, Social Workers and other front-line practitioners including SDS support and advice agencies operating under contract, have the knowledge and confidence to advise people living with dementia on SDS.
- Work with people living with dementia and their carers to co-produce learning modules for advisers.





## Story 1 - Robert and Joan

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Robert and Joan were married for over 40 years. They both retired from professional jobs with plans for a happy retirement, travelling and enjoying a fulfilling life. They had 2 married children, 4 grandchildren, a close family and a wide network of friends.

### Dementia and the impact

In 2007 Robert was diagnosed with an early onset, rare form of dementia, the reverse of more commonly recognised dementias. With Robert's dementia there was a loss of conceptual knowledge affecting long term memory, but his short-term memory remained largely intact. With this kind of dementia, the risk is very high as the person doesn't understand or recognise how things work including road signs, traffic signals and other warnings. The person needs to be assisted with many aspects of daily life although they want to continue as normal. This can make it extremely difficult for the person's carer. Robert passed away in 2015, 7 years after he was diagnosed.

*'He functioned well until the last year. We walked every day and he played dominoes and Patience and did Sudoku right up to the end.'*

Joan cared for Robert, at home for 7 years. Initially Doctors wanted to do regular memory tests on Robert, but Joan realised that these were distressing and intrusive and led to no additional treatment or intervention.

*'If you are doing a test it has to have a purpose...not just to tell people they are getting worse.'*

For the first 4 or 5 years after Robert was diagnosed the couple had little support from professionals and relied on family and friends.

*'They just left you to it.'*

Robert needed a lot of support with all aspects of his life. He was determined to continue to live his life as best he could, but his lack of comprehension and insight put him at risk.

During this time, the family regularly travelled to places that were familiar to them. During one of these trips Joan recognised Robert's vulnerability after an incident that was a change to their usual travel arrangements. At that moment she realised it was time to put plans in place for both of them. Life was becoming more complicated and she was worried about her own health, how long she could carry on caring for Robert and what would happen to Robert and the family if anything happened to her. This realisation prompted Joan to contact social services on the couple's return home. After speaking to a less than helpful duty Social Worker the involvement of outside agencies seemed to be a real 'palaver' and Joan continued to support Robert on her own for several months.

*'I thought I just can't be bothered with all this.'*

*'Self-referral to social work is designed for crisis situations.'*

### Care and support

Then one day Robert collapsed at home, the GP was called, and they made a referral to social services.

*'Once the crisis has happened it is a different thing altogether.'*

Robert was assessed to see if he was eligible for council funded care and Joan was assessed to explore her needs as a carer. Joan was clear that the couple were aiming for self-directed support. The assessment process was complicated, and the Social Worker had little or no awareness of Robert's condition.

*'The Social Worker had great difficulty doing the assessment...I had to give them an article to inform them about the condition.'*

Following the assessment, the couple were allocated 4 hours of support every week day for Robert's care and an additional 12 hours per week for Joan's respite - 32 hours of council funded care and support a week. It was recognised that Joan would be supporting Robert at other times. The Social Worker explained SDS to Joan and Robert, the 4 different options and how they might work in practice.

At this stage there was a real disconnect between Robert and Joan's needs and what was officially available. The assessment process was geared towards people needing help with personal care and was totally task and timeslot focussed.



This did not work for the couple at all as Joan was best placed and able to support Robert with his personal care and due to Robert's condition, this couldn't happen at set times.

*'He would just take off his clothes when he was ready for a shower. It needed to be now.'*

*'It sometimes took me all day to get Robert shaved. A little bit here and a little bit there whenever he was calm and would let me.'*

What Joan needed was a regular break from caring and from the responsibility of keeping Robert safe and well. What Robert needed was an opportunity to keep as active and independent as possible, participating in the things he enjoyed. The Social Worker recognised this challenge, but the system required that she and the care agency describe activity in terms of personal care tasks while agreeing with Joan that the reality was very different.

In addition to the Council funding, Joan decided to 'top up' with the couple's own money to ensure there was enough resource to get Robert the help he needed in ways that really worked for him.

### **The journey to Self-directed Support (SDS)**

Joan was aware of self-directed support through her work and gained more information from the Social Worker.

*'I had been working in the field of dementia, so I knew.'*

She was attracted to the model because she thought it might offer Robert the help he needed to remain as independent as possible for as long as possible, enjoying the things he loved.

*'I wanted SDS at an early stage to enable Robert to live as independently as possible. But it is only available at crisis point and that is wrong.'*

Joan chose Option 1 and opened a new bank account from which to manage both the Council and top up funds. At first this money was used to buy care services from a care agency and Joan set the terms under which the agency would operate. At £18 per hour, the rate of the agency was more than the £13 per hour rate paid by the Council so Joan and Robert used some of their own money to make up the difference.

Initially the arrangement with the agency was fine but it was never ideal. Joan had been clear in her terms that they wanted more mature carers who could relate to Robert as an older man. In practice many agency carers were young, and the consistency wasn't as good as anticipated. In addition, there were some serious problems such as one carer being unable to help Robert to use the toilet for religious reasons and another stealing from the couple.

*'I felt let down.'*

### Employing staff

Joan talked to one of the agency carers and discovered that they were being paid just £7.50 of the £18 per hour charge. Joan realised that by employing her own staff she could make the money stretch much further and get better support for Robert at the same time.

*'I went back to the Social Worker and said "I'm going to save you money by employing my own person."*

Joan learned from other people that Gumtree was a good place to advertise for staff. She developed an advert, job description and person specification and advertised on the site.

*'I was flooded with applications.'*

She shortlisted 6 candidates and told them to get in touch by phone, weeding out people who showed they were not person-centred in the process.

*'One person rang, and I could hear someone in the background. They explained that it was someone they were supporting. I thought - they are ringing to apply for a new job when they are supposed to be caring for someone. They would probably do the same if they were caring for Robert.'*

Joan interviewed 4 people in a room at a local leisure centre. She did this on her own and thought the arrangement worked well. Two people were employed. Joan was clear what was required to become a good employer and ensured the staff had clear terms and conditions including a contract of employment and annual leave. Some template paperwork came from a local Direct Payments support agency. Joan and Robert's daughter is an Accountant so was able to advise on employer matters and managed the payroll for the employees. Joan was very clear what she needed to do to keep records and have an audit trail for the money.



*'I still have all the paperwork in case they come back to me.'*

Joan asked the Council if she could get places for the new employees on their training courses e.g. moving and handling. Staff worked 7 days a week from 8am to 1pm with Joan using her and Robert's own money to top up the council funding.

*'If I didn't have money myself I wouldn't have been able to do it. I needed more hours than they would pay for.'*

### **The impact of Self-directed Support**

The carers were tasked with helping Robert enjoy activities, remain as independent as possible and ensure he was eating well. In addition, they were to give Joan a break and help with some household tasks.

*'I was able to go out in the morning'*

Specifically, this involved playing games with Robert, helping him go out for walks, reading, ironing and cooking food in small portions. The arrangement worked very well and gave Joan real peace of mind.

*'It worked like a dream'*

*'They knew everything about the house. It was such peace of mind for me'*

Sadly, Robert died soon after the arrangements were put in place and only had his own small team of staff in place for 2 months of his life. After Robert died, and at a time when she was newly bereaved, Joan faced real challenges connected to the SDS.

*'After he died I had to end the contract with the staff, making people redundant and doing all the paperwork. It was the worst time for such bureaucracy.'*

## Story 2 - Ray and James

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James and Ray were happily married for over 30 years with 2 adult daughters and a large extended family including 26 nephews and nieces, many of whom lived nearby.

*'Family was everything.'*

James was an active man, a contracted electrician who worked hard all his life and ran his own successful business. James was popular, known for his warmth and generosity. Ray is an active and vibrant woman who had a successful career in pharmaceuticals. The couple had a really good life with lots of family time, social activities and travel. James passed away in February 2018.

### Dementia and the impact

In 2011, James' Mum passed away and the couple refurbished her house. It was during that time that James noticed a tremor in his hand. At the same time, he seemed unsettled and out of sorts – he was 50 years old. Ray suspected that James was having challenges with his mental health and that the bereavement and other life challenges were simply too much. After taking medical advice James was referred to a psychiatrist and 2 years of misdiagnosis and confusion followed.

*'For 2 years doctors thought he was having a breakdown, but we knew they were wrong. Our daughter is a doctor and together we did our research. We were pretty sure we knew what James had but no one would believe us.'*

The family were convinced that James had an extremely rare form of dementia called Corticobasal Degeneration (CBD) and frontal temporal lobe dementia, a condition that affects less than 100 people in the UK. His symptoms of physical twitches, particularly in his hand, combined with anxiety and other mental health problems mirrored those of the condition almost exactly. With family pushing and persuading the doctors, James was eventually referred to a neuro-psychologist and then to the 'early onset' dementia team.

His condition declined with James becoming psychotic and his personality changing as a result. He became angry, paranoid and violent. He still did not have a diagnosis and was receiving no treatment.



James was sent for brain scans to try and diagnose his condition, but the results never arrived. After 6 months of chasing and pushing Ray discovered that James' surname had been misspelt in the social work system, therefore no help arrived. The brain scan test results were not delivered by the 'early onset' dementia team and the family received no explanation. During this time the situation at home was becoming worse and worse with James becoming more unpredictable and violent.

*'You lose sight of who your husband is.'*

Ray asked for help from both health and social care agencies but was told that without a diagnosis no help was available. She was still working, and the strain was huge.

*'I was trying to go to work to pay the bills.'*

To try and learn more about how best to support James, Ray attended a course alongside dementia professionals from the local council. During sessions Ray regularly shared stories of life at home with Ray which were shocking and extreme. Despite all this no-one from social services offered to help.

*'Without a diagnosis no one would do a referral to social services...and even though we knew what was wrong we didn't have a formal diagnosis to back that up.'*

The family did receive input from a Community Psychiatric Nurse (CPN).

*'The CPN would not let me stay at home alone with James as she felt that I was in danger. My daughters and daughter in Law stayed with me and the CPN told them to hide all the knives in the house.'*

As things declined the dementia team made a referral to social services and they became involved, beginning an assessment with a view to offering support to the family.

*'I never saw a Social Worker until just before James was sectioned and we were in total crisis.'*

Things came to a head in November 2016 with James having a psychotic episode which resulted in the Police being called and him being sectioned under the Mental Health (Care and Treatment) (Scotland) Act 2003 and admitted to a locked ward in a local in-patient unit.

Also, in 2016 a Neurologist with the dementia team first diagnosed James as having Corticobasal Degeneration – the condition that the family had suspected was at play 4 years earlier. Despite this, the diagnosis wasn't actually confirmed until May 2017, less than a year before he died.

### Care and support

Apart from one brief period at home, James was in hospital for 8 months. Ray spent time at the hospital every day helping with James' personal care as he refused help from the female staff on the ward.

While he was in hospital social services stayed involved with the family, undertaking an assessment with a view to arranging a care package for James once he came home from hospital. The CPN also continued to be involved.

In June 2017 James was discharged from hospital. He was mentally stable but had deteriorated cognitively, lost his balance and was no longer able to walk. He needed a lot of physical help and Ray took extended time off work to make all the care arrangements, attend meetings and care for James.

Social services suggested that it might be better if James moved into a care home, but this was not something the couple wanted or thought was appropriate.

*'They wanted James in a care home...she approached a care home behind my back.'*

*'He was 55 and had awareness. There was no way I could put my husband into an elderly care home.'*

The couple got a huge amount of support from a local support organisation who Ray sees as her real support and salvation.

### The journey to Self-directed Support (SDS)

Ray had connections to Alzheimer Scotland and this meant she was aware of SDS and knew what it might offer her and James. Ray talked to the social worker about SDS before the situation became a crisis and James went into hospital.

*'I asked for help and mentioned SDS...but she kept putting me off.'*





In May 2017, after a series of unsatisfactory interventions and delays the family were offered a care package of 35 hours per week. This was a temporary arrangement designed to be amended as and when James' condition deteriorated. Ray was clear that she wanted to use SDS to manage this package of care for James. She felt that this was the only way James would get the kind of personalised support he needed, to stay as independent as possible for as long as possible.

*'I wanted company for James, and to know he was safe while I went to work.'*

### **Self-directed Support**

Ray was interested in Option 1 but was told that this wasn't possible because she did not have Lasting Power of Attorney for James. Instead the family decided to go for Option 2 with an arrangement with a care provider suggested by the Council. Ray was clear that she wanted James to be supported by male carers of a similar age to himself and made arrangements with the care provider for this to happen.

*'He was just so private, he just couldn't have coped with young female carers.'*

James needed a lot of support, including help to stand and with all his personal care. The care package arranged by the council only provided for one carer, 4 days a week. Often Ray would help the carer to physically care for James, to move and stand and get in and out of bed. On the days when either the carer or Ray was not around James was supported by one person.

*'Both myself and the carer were left to lift and pull James on and off the commode and in and out of bed while we were on our own. One carer hurt his back and lost time at work. Our situation was unmanageable, and everyone was in danger of being hurt, including James.'*

After more delays and difficulties, the social care budget was increased, and the local Palliative Care Team began to help the family. This was in addition to the care from the care provider already in place and funded using Option 2. For the first time in 5 years James now had support every day of the week.

*'Once they conceded that James was dying they sent in the Palliative Care Team. They were a godsend.'*

In November 2017 James became unwell and was admitted to hospital soon after. He eventually moved to a local hospice where he received excellent care.

*'The hospice was amazing.'*

As soon as James was admitted to hospital, social services withdrew the SDS budget immediately, meaning that the consistent staff who knew James well would no longer be available when and if he returned home. James died in the hospice 3 months later.

### **The impact of Self-directed Support**

Ray is clear that SDS gave her the opportunity to get James the help he needed in ways and at times that worked for them as a family. It enabled him to stay at home rather than move to a residential setting that was not right for him.

Ray and James' whole story is one characterised by a need to battle at every stage of the journey to and experience of SDS.

*'It should be person centred and it is absolutely not.'*

Despite this Ray is clear that SDS offers something that is worth striving for.

*'SDS is the only way we are going to get change. Unless we keep using it...or trying to use it then it will get lost.'*



## Story 3 - Ella and Peter

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Ella and Peter have been happily married for over 50 years. Ella was a strong and successful woman with a long and successful career in teaching and a lifetime of volunteer work connected to her local church. Ella loves music, plays the piano and likes to sing. She also likes to keep active, enjoying swimming and long walks in the country. Peter was also a teacher. The couple had a wide circle of family and friends and liked to socialise and contribute to their local community.

### Dementia and the impact

In 2011 Ella was diagnosed with dementia after a trip to the GP and a referral to the local Memory Clinic. The diagnosis was [Frontotemporal dementia \(FTD\) with aphasia](#), a progressive disorder which affects behaviour, language skills and movement.

Initially the couple continued to live life as they had before the diagnosis, with Peter supporting Ella as needed. At first Peter continued to work part time as a supply teacher but over time this became more and more difficult.

*'I couldn't totally rely on getting cover (from carers).'*

Since leaving work the impact of the loss of income on the couple's finances has been considerable.

As Ella's condition has worsened the couple have noticed that friends have dropped away and this has been very hard for them both.

*'When you get dementia, your friends leave you.'*

The couple recently had their 50<sup>th</sup> wedding anniversary and Peter used the occasion to have a party, inviting friends and family and requesting donations to charity rather than gifts.

## Care and support

By 2014 Ella's condition had deteriorated and she needed more support. The couple had their first contact with the local council who did an assessment and developed a care plan for Ella. A Care Broker visited the couple at home and recommended that a local homecare provider be instructed to help Ella at home every morning and afternoon. Initially this arrangement worked well but over time it began to be less effective.

*'They began to drop off with carers going off sick and other problems.'*

Then, without warning, the carers stopped coming to the house and the provider said they could no longer deliver the service they had been contracted to deliver.

Alongside the help at home Ella began to attend a local day centre run by the council for older people. Ella went there for 2 days each week. Ella enjoyed her time at the centre and it gave her some time out of the house, enabled her to socialise and engage in activities she enjoyed such as music and art. This arrangement also worked well initially but over time, and as Ella's condition worsened, Peter was told by centre staff and other professionals that his wife was no longer suitable for the centre.

*'They said she was becoming difficult to handle at the centre. I attended case conferences where they accused Ella of assault. It turned out she hadn't assaulted anyone - instead she was banging on the table and shouting when she was confused by the noise. They just didn't seem to understand dementia and how to support someone well.'*

In order to keep Ella in a place she enjoyed, engaged in activities and meeting people Peter offered to pay for extra support. He identified a carer through a local organisation who had extensive knowledge of dementia. He proposed that this carer, privately funded, accompany Ella to the centre and support her on a 1:1 basis – taking the strain off centre staff. The offer was refused, and Ella was 'expelled' from the day centre to be supported at home by Peter.

*'When we lost the day centre our world fell apart. I just thought... what are we supposed to do now?'*

More recently the couple have discovered that Ella could attend any local day centre on a 'drop in' basis and this is something they are exploring.



In addition, Ella has had contact with local health services with the involvement of a psychiatrist and CPN and treatment for a series of urinary tract infections (UTIs). The couple's experience of health services has not always been positive with a misdiagnosis of psychosis leading to the prescription of the wrong medication which affected Ella badly.

*'I picked her up one day and she was like a zombie.'*

It has been recommended that Ella consult a psycho-geriatrician, but this specialism is not available in her council area. Peter has identified one, a distance from their home, and is hoping Ella may be able to have a consultation in the near future.

Sometimes Peter needs a break from caring for Ella but there are no residential respite services locally that can be booked in advance. This means Ella needs to travel to another area, over the border into another council area for short breaks.

### **The journey to Self-directed Support (SDS)**

In 2016 Peter heard about self-directed support through a contact at the local carer support organisation. He asked for more information and was sent a booklet containing information about the 4 SDS options. Peter was interested in Option 1 and believed it might offer them help and support in ways that worked for Ella and for them as a couple.

Discussion started with the council, who developed a care plan for Ella. After some months conversations began about how Ella's needs might be met using Option 1 and Peter immediately spotted a disconnect between the rhetoric of SDS and the reality.

*'The information from the carer support organisation was talking about personalisation and creative approaches to care. Once I started talking to the council about this they were saying 'we are only going to fund personal care.'*

The council offered Ella a personal budget of £15,000 per annum which worked out at something like 22 hours per week of care. This was enough to meet Ella's basic personal care needs, with Peter also supporting, but was not enough to enable Ella to live a full life doing things she enjoys. After more discussion Peter decided to take the resources offered by the council for Ella's personal care and then 'top it up' with an additional £15,000 per annum of the couple's own money.

## Self-directed Support

Peter set up an arrangement with the local Centre for Independent Living (CIL) a charity and user-led organisation (ULO) who have a contract with the council to advise and support people who choose SDS. This involved him establishing a new dedicated bank account in advance of the SDS arrangement.

Peter decided to take a mixed approach to the care that Ella needs, with some help coming from 2 local care agencies and the rest from a small team of personal assistants, employed by the couple.

The council have an agreed rate of £12.80 per hour for care workers. In practice the money goes from the council to the CIL and they help Peter and Ella to employ their own staff and manage all the payroll and administrative arrangements. As part of the arrangement the CIL helped Peter to take out employer's liability insurance. The CIL also manages invoicing and financial arrangements with the care agency, paying them directly. At the end of the month the CIL tells Peter how much is in the account and how much he needs to top up with his own funds.

Initially the arrangement gave Peter real time control of the personal budget monies allocated for Ella's care by the council. More recently Peter lost the ability to manage the account on his home computer, which he found a challenge.

*'It is a really good service apart from the fact that I can no longer see the money in real time. Now I have to phone the CIL to find out how much money is in the account and that is a problem. It is not how self-directed support is supposed to work. The benefits outweigh the challenges though so we have to manage to live with any inconvenience.'*

With support from the CIL the couple employ 4 staff, all part time. The CIL used Gumtree, Job Centre Plus and university jobs boards to advertise opportunities. Peter selected workers who were able to bring different skills into Ella's life, helping her to enjoy life, stay active, pursue interests and stay social and connected. The most important quality for Peter and Ella was that a staff member had to be an optimist with a 'can-do' attitude.

*'She spends time in the swimming pool and gets lots of walks and time in the sunshine. She does music and art therapy. She is happy and active and has people interested in her. Her support is personalised and holistic and enables her to have a good life.'*



One staff member is a dementia specialist, with training from and experience with Alzheimer Scotland. The couple have been creative about how they get the help that Ella needs and not focussed too heavily on the personal care element of her needs.

*'One staff member is a cook and hairdresser as well as carer. We pay more, but Ella was paying £90 per month to have her hair done so we save on that and it is worth the additional expense.'*

However, none of this would be possible without the couple supplementing the personal budget considerably.

*'By topping up we can do a lot more.'*

This creative approach is very different to the quite traditional view of social care taken by the council but one which they are largely willing to support and learn from.

*'We have worked together and taught each other a lot.'*

Recently the council have helped Peter organise training that his staff can access. This includes training on dementia and moving and handling. Peter pays for the training from the SDS personal budget.

Peter also uses some of the budget to pay for Ella to take a short break at a residential service for one week every month. This gives Peter a break from caring for Ella.

## **The impact of Self-directed Support**

Peter is clear that SDS has had a very positive impact on his and Ella's lives. It enables Peter to direct care and support and offers Ella the opportunity to live a full and active life. It extends the support available past the limited boundaries of personal care.

It has allowed the couple to be flexible and creative about the people that provide the care and support, the skills they have and the approach they take.

The financial contribution of topping up the budget has had a real impact on the couple's finances and Peter has been forced to apply to funding trusts for help. More recently he has been working with MECOPP carers centre who offer legal advice on SDS issues to people and their families. Early indications are that Peter and Ella may be entitled to a higher personal budget which could help the couple's financial situation considerably.

*'I was told I was getting as much as I was allowed but the MECOPP lawyer's advocacy has made all the difference.'*

## Story 4 - Zoe, Margaret and Jean

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Zoe is a strong, articulate woman with a successful career in running her own international business. She is a wife and mum.

In 1995 when this story starts, Margaret was a proud and independent woman. She had sold up the large family home, down-sized to a smaller house and was making a new life for herself after retiring from a happy and successful professional life. She adored her children but difficulties in her personal life had increased her reserve and she was often lonely.

By 2013, when Margaret passed away, she was at home where she had always wanted to be, happy and well connected with many interests and numerous strong relationships.

*'This is a story about love, and about hope. In a way, dementia gave my Mum back to me.'*

### Dementia and the impact

In 1995, six weeks after the birth of her first child, Zoe was called in the middle of the night to be told that Margaret, her Mum, had been found by the police, wandering and disorientated near her home. She was diagnosed with a urinary tract infection and then, dementia.

Margaret lived over two hundred miles away. She was on her own having separated from Zoe's Dad years earlier. After a three month stay in a psychiatric ward, Margaret was discharged back to her own home and support was down to Zoe and her siblings.

For five years after her diagnosis, Margaret stayed in her own home, managing well with support from her friends, Zoe and her siblings. Zoe cobbled together an informal support network for her Mum that included the supermarket manager and a local taxi-driver and that worked well for a while. But in 2000, Margaret admitted that she felt scared. She wanted to be closer to her children but she didn't want to be a burden. So she left the place where she had lived for the last fifty years, left her friends and moved north, close to Zoe.

*'Mum told me she was frightened, living alone and I knew we had to do something.'*





Following the move, Margaret went back and forth to hospital for more tests that would confirm her diagnosis. The Powers of Attorney had to be re-drawn and re-ratified. Margaret's confidence plummeted. With no friends around her, in a strange place and with only Zoe for company, she sank into a depression.

Zoe became the archetypal 'squeezebox' carer: working full time, with a young family and a Mum to support. The Community Psychiatric Nurse (CPN) was Zoe and Margaret's only point of contact. She was a leader in her field who had dedicated her career to care in the community. The CPN called in every three months. By the end of the second year, seven years post diagnosis, she suggested that Margaret needed more support. Zoe says that the CPN was a godsend:

*'She was wonderful. If I had a crisis, I would turn to her. She was the only person who said "leave it to me and I will get back to you."'*

### Care and support

The CPN brought in home care via social services and told Zoe about Attendance Allowance. Margaret now got three visits a day from a team of three carers in addition to daily visits from Zoe. With continuity, the carers became friends, but each visit was quite short, and Margaret began to wander.

When Zoe was abroad on business, she booked and paid for additional support for Margaret from a local care agency. Despite detailed briefings, the care provided by the agency was deeply flawed. Carers were cancelled, they didn't know Margaret's name or anything of her background. Increasingly, Zoe found that she was having to trouble-shoot care around the clock.

Then in 2004, cost pressures forced social services to bring in a change of practice and continuity and consistency ended for Margaret. There were no more teams, no regular visiting times and no information to show who was coming or when. Margaret thought that her home now belonged to the succession of strangers who came and went, and she retreated to her bedroom. She stopped eating, became dehydrated and didn't take her tablets, despite prompting. Margaret needed help 24 hours a day, 7 days a week and Zoe started working later and later at night because the day was spent in and out of her Mum's house orchestrating care. Zoe recruited two private carers to provide more companionship and to 'anchor' the support provided by social services.

Margaret's wish, clearly expressed in her Power of Attorney, was to remain at home. Nonetheless, Zoe undertook to visit each of the local care homes, thinking that if she could not care for her Mum, or ensure her wellbeing or happiness, her duty was to secure the best care elsewhere. Yet Zoe, knowing her Mum's background, doubted that Margaret would survive the trauma of being placed in residential care. They had reached crisis point.

### The journey to Self-directed Support (SDS)

At the point of crisis, the CPN introduced the idea of self-directed support (SDS) and in particular Direct Payments or Option 1. Zoe thought that this might be a way to get Margaret the help that she needed, provided in ways that worked much better for her.

*'It seemed at that stage to be the least worst option!'*

The CPN and Zoe developed a care plan for Margaret and took it to social services. The process was unclear and further complicated by the absence of a Direct Payments Co-ordinator who was off on long-term sick leave. Eventually, social services offered a budget of £400 a week.

Zoe had a plan to employ a team of staff to provide the care that her Mum needed. Having paid care agency fees she knew that £400 a week wouldn't be enough to put together a team and to cover National Insurance and tax liabilities. Zoe appealed the social services' decision, and this was rejected two more times. Months passed before the case was handed to a new and supportive Social Worker. Zoe, the CPN and the Social Worker mapped out a realistic care plan based on Margaret's identified needs, petitioned social services and were awarded a settlement that covered 65% of care costs.

### Self-directed Support

The plan was for Zoe to use the budget to recruit and employ a care team for Margaret with Zoe acting as 'anchor-man', providing direct care for her Mum, managing the household and managing and leading Margaret's team.

The team comprised four carer/companions, one of whom stayed in the house four or five nights a week. Carers were of all ages, all backgrounds and with a wide range of interests and skills. What they had in common was kindness, a sense of humour and a willingness to focus on happiness, self-esteem and on embracing possibility rather than mourning loss. Zoe was clear from the start that attitude and aptitude were far more important than qualifications:



*'We didn't necessarily want carers or ex-nurses. The caring was all about Mum and how could you be pre-trained in her?'*

The team remained the same for eight years. They worked effectively together, supported each other and did everything possible to expand and enrich Margaret's life. Zoe worked alongside the team, ensuring that they had a shared vision and approach and encouraging new ideas and suggestions. The team developed a kind of 'happiness strategy'.

*'The team came with me every step of the way and we examined every aspect of Mum's life quite forensically to see how we could do things better. We thought about her diet and hydration and her environment. Was it appropriately light/dark/quiet/cool/warm? Were there flowers? We considered how to keep Mum mobile and encouraged her to keep walking. We talked about Mum's style and her pride in her appearance: clothes were all favourite colours, scents were those she loved, make up, hair, jewellery. We planned parties and invited guests. We took her out in the country to keep her connected and explored local places that would be welcoming and accepting...even if Mum turned up in her pyjamas!'*

Zoe and the team realised that if you are prepared to take responsibility and to think a little ahead, ordinary people are often very welcoming and want to make people like Margaret feel included.

Every staff member developed their own relationship and connection with Margaret without needing direction from Zoe. When she lost conventional language, they understood her sounds and signs perfectly because they knew her so well.

*'One person shared a love of poetry with Mum and had skills in aromatherapy. One chatted about her boyfriends...Mum loved to gossip. One found old films and favourite TV classics and bought a whole load of box-sets that Mum just loved. Getting up in the morning was a ritual of singing hymns, old folk songs and ballads from the musicals. We learned songs from South Pacific and the big band days. And Mum adored to have babies and her grand-children in the house.'*

Every person in the team connected with Margaret on a personal level and real and lasting, reciprocal relationships were formed.

*'One day we realised that there was something that we had overlooked. We were all busy doing things for Mum. But we had neglected the fact that she wanted to do things for us too. She wanted to make us laugh. Above all, she wanted to show that she loved us. That was the last and most important part of making her happy. We needed to learn that care is about receiving as well as giving.'*

Over the years, Margaret had falls and periods of ill health. In total, she was admitted to hospital five times. After the first hospital stay, Margaret came home with a sharp deterioration in her mood and mental faculties. The next time, with the agreement of the team, Zoe approached the Chief Executive and the ward Charge Nurse to ask if Margaret's team could provide care for Margaret while she was in hospital. The team recognised that continuity was key.

*'We kept her world the same. We could deliver practical hands on care at times and in a way that suited Margaret. Food was the same, conversation was the same, the faces around her were the same – and cuddles were the same!'*

Five years before Margaret died her team were supporting her 24 hours a day. By this time, Zoe had had to give up work and was supporting Margaret in addition to another relative who needed care. In the last year of Margaret's life, she was diagnosed with gangrene. Zoe was asked about amputation but she decided that keeping her Mum comfortable and optimising her quality of life was more important. She knew that her Mum was dying.

Zoe spoke to the family GP and District Nurses to ask if they could help the team nurse Margaret at home, and care for her to the end. Zoe gathered the team together to explain the situation, and to give carers a free choice as to whether they were willing and able to continue. Everyone wanted to stay, to support Margaret, Zoe and each other.

*'The palliative care nurses were fantastic and found the right cocktail of medication to address the pain without turning Mum into a zombie. The District Nurses were also wonderful: always on hand, changing the dressings, trying to find out the best way to manage Mum's condition and keep her comfortable. And we couldn't have had a better or more caring GP. As for us, we just went on doing what we had always done, making Mum feel special and connected and happy.'*



Margaret died in Zoe's arms in 2013. Everyone who had cared for Margaret but who were not able to be with her on her last day, called in to hug her and to say good-bye before she left her home for the last time. Caring for Margaret had been one of the most transformative experiences in everyone's life.

*'Dementia might have come like a thief in the night, but for all its evisceration, it failed to rob Mum – and us – of her sense of self or what made her special'*

After Margaret died, Zoe felt a huge responsibility to the family of carers who had remained so devoted to the end. During their shared care, Zoe had nominated carers for awards, written about the excellent standards of care given and the team's holistic approach to delivering first class dementia care. Zoe sought out the top agencies in care provision, and set up a meeting to introduce Margaret's former carers.

*'I'm fully cognisant of the fact that I was their employer and I want to do whatever I can to ensure that people who have given so much to Mum and to me, don't lose out in terms of their career. All our carers know that they can call or email me at any time and all of them have written references as a testament to the fantastic support they gave.'*

### **The impact of Self-directed Support**

Zoe is clear that SDS gave her the opportunity to help Margaret live a full and happy life right until she passed away.

*'We thought hard about what made Mum happy. Then we worked together to make that happen...I couldn't have done it any differently. Mum wanted to stay at home. I couldn't have continued without SDS.'*

The flexibility that SDS, and Option 1 in particular, gave the family and care team was valued highly.

Zoe took the lessons she had learned from her journey with Margaret and used them when her mother in law, Jean, was also diagnosed with dementia. Unlike Margaret, Jean wished to live with the family:

*'We used SDS again and chose a direct payment. We employed a different team of carers but they were carers whom we knew well. They shared the same 'can-do' attitude with kindness, compassion and respect.'*

*'Toward the end, what we could do diminished, but the carers never gave up. You could see that my mother-in-law loved them and gleaned great comfort from their gentle head, hand and foot massages.'*

Jean passed away in 2018.

Zoe knows that the teams of carers who cared for both Margaret and Jean learned a huge amount from the experience and grew in confidence.

*'All our carers made magnificent contributions in ideas and the quality of care that they gave. I know that they're using the same approach with people whom they're caring for now.'*

Supporting Margaret and Jean in this way, managing the personal budgets and navigating the system has been a life-changing undertaking for Zoe. Zoe left a highly paid job to care which has had a lasting impact on family finances.

*'I'm lucky, I'm back in work but it's not the work I would have chosen and I earn less than 10% of the turnover I generated over a decade ago. There's no track, no real careers advice for former carers apart from at a very basic level. My loss of career is almost incalculable. But how can you walk away from someone who gave so much for you, who appointed you to safeguard their wishes - and feel comfortable with that.'*



## Story 5 - Grace and Ann

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Grace is an older lady who lives in Scotland. Her daughter, Ann is her main carer. Towards the end of 2014 Grace was unwell and was admitted to hospital for treatment.

### Dementia and the impact

When she was in hospital the staff expressed concerns about Grace and her cognitive ability. Further investigations following Grace's discharge from hospital resulted in her being diagnosed with Alzheimer's disease in early 2015.

### Care and support

Grace was discharged from hospital with a short term 'reablement' care package designed to help her regain her independence. The care was provided by staff from a local homecare provider and funded by Grace's local council. Grace was getting 4 calls a day from care workers, 7 days a week. Each visit was scheduled to last a maximum of 30 minutes.

On assessing the care package at the end of the reablement period, it was deemed that Grace needed the care to continue on a permanent basis. This was supported by the subsequent diagnosis of Alzheimer's Disease.

The care provided was fine but not excellent and there were some issues and problems. This included challenges with communication and a delay in informing Ann about important aspects of Grace's condition or care.

*'Generally speaking the care has been reasonable but no better than that.'*

Grace also had glaucoma and other eye problems and needed help to administer eye drops. This seemed to be a real challenge for the care provider.

*'It took a bit of time and effort to get that in place.'*

At no time did anyone mention that there might be alternative ways of meeting Grace's needs and Ann believed that the only option was the one large homecare provider they were already working with.

*'No one ever told us that there were alternatives or another provider or another way of doing things.'*



Ann had concerns that Grace needed more and different support than she was getting from the care provider and was considering whether to purchase additional support for her Mum, using personal funds.

*'What she is getting at the moment is allowing her some level of independence in her own home, but without me I wonder how sustainable it would be in the long term.'*

### The journey to Self-directed Support (SDS)

After Grace's dementia diagnosis, Ann got in touch with Alzheimer Scotland and TIDE, an organisation that empowers carers of people with dementia. Ann was hoping to gain information about her Mum's condition, how best to navigate the health and social care systems and how to support Grace well. During discussions Ann learned about SDS and the concepts of personalised approaches to care and choice.

*'Initially I probably didn't consider it as a possibility but then in talking to people about it and the fact that it could be tailored I began to think it might.'*

Ann found out about the different SDS options and considered which would work best for her and her Mum.

*'Once I found out more I thought maybe Option 2 might give me a chance to try different providers. I knew it would probably cost more but was willing to add money to it.'*

At this stage Ann was clear that option 1 would not work for her and Grace.

*'People said 'what about Option 1', but I work full time and don't have time to take on board the administration it would entail.'*

Ann was hopeful that SDS might unlock the possibility of additional care that was specially tailored to Grace's needs.

*'The girls are very good, but they are just so run off their feet. It would be great for Mum to have more time without having to ask for it. She did wash her own dishes etc but she now needs more help and the carers just don't have the time to help her with that kind of thing.'*

Ann realised that the only route to SDS was through a Social Worker. Grace didn't have a Social Worker at that time so this was a challenge.

*'To take it forward I had to go through a Social Worker and Mum didn't have a Social Worker. I had to contact social services, ask for Mum to be allocated to a Social Worker and then for her to go through an assessment.'*





Through this process Ann was clear that she wanted SDS for her Mum and Option 2 in particular. She did not get a positive response from the allocated social worker.

*'The Social Worker wasn't entirely favourable about SDS.'*

When Ann did some investigation, she began to have concerns that in her area SDS was seen as an approach to be taken by younger people rather than something made readily available to people of all ages.

*'I have heard that our Council don't really encourage people who are over 60 to use it.'*

Despite the barriers put in her way Ann decided to keep trying to get SDS for her Mum. She remained convinced that this new approach could get Grace more and better support.

*'Eventually I said 'I am entitled to at least look at this'. I stood my ground and said I wanted to see if it would be possible.'*

## **The impact of Self-directed Support**

The Social Worker has almost completed Grace's assessment, but the process is slow and there are some small aspects still to complete.

Ann was told that using Option 2, any care provider she chooses to use must be on the council framework. She requested a copy of a list of providers that are on the framework, but this was not supplied by the council. Ann talked to a local support organisation and they were able to give her the information about providers that she needed to make a choice. Even then she realised that things were not straightforward.

*'When I finally got the list, I found out some of the providers on it didn't offer care to people living in Mum's area. When I did find some providers that were in the area they couldn't or wouldn't support Mum.'*

To try and tackle this issue Ann asked the council if she would be able to use Option 2 to contract with a provider who is not on the council framework. She was told that the council might be willing to consider this if Ann developed and presented a case.

*'They said if I presented a case for using another provider that they might be willing to look at it.'*

Ann did find a provider that she thought might be able to support Grace, using Option 2, if the council authorised the arrangement. After some discussions with the new provider Ann realised that they couldn't provide everything Grace needed at times and in ways that worked for her and the family.

*'Mum goes to a day centre 2 days a week and the provider couldn't fit in with the times for that. I didn't feel it was worth preventing her from going to day centre just to fit in with the care provider.'*

At that stage Ann didn't know what else to do so her quest for SDS for her Mum has come to a bit of a halt.

*'A number of things have prevented me from taking it any further. I have taken my foot off the gas but haven't turned the engine off. It has been a frustrating process and I haven't found it user friendly.'*

## Thanks to:

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## Getting in touch

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