Self-Directed Support Pilot Project, Ayrshire
Final Report, May 2009 to July 2011

Yvonne Stewart, Project Manager
Acknowledgements

We appreciate the help and support of many people in carrying out this project. Thanks are due to everyone who participated in the pilot, especially the individuals with dementia, their families, the link officers from each local authority, the health board, individual care managers and other professionals who shared their personal experiences and views of SDS. We also thank the SDS Team at Scottish Government and our colleagues within Alzheimer Scotland.

Project Steering Group Members

Helen Wilson - Carer
Isabel Marr – Ayrshire & Arran Health Board
Karen Turner – Ayrshire & Arran Health Board
Alan Brown – North Ayrshire Council
Mary McLelland – North Ayrshire Council
Liz Vance – South Ayrshire Council
Sheila Murdoch – South Ayrshire Council
Claire Mills – East Ayrshire Council
Jane Duffy – East Ayrshire Council
Kate Fearnley - Alzheimer Scotland
Julie Sinclair - Alzheimer Scotland
# Table of Contents

**ACKNOWLEDGEMENTS**  
Project Steering Group Members  

**FOREWORD**  

**EXECUTIVE SUMMARY**  

## 1. INTRODUCTION  
1.1 Background  
1.2 Core values and principles of self-directed support  
1.3 Self-directed support in Scotland  
1.4 Self-directed support and people with dementia  
1.5 The journey to long term residential/nursing care  

## 2. THE AYRSHIRE SELF-DIRECTED SUPPORT PILOT PROJECT  
2.1 Project activities  
2.2 Person centred planning  
2.3 Other support provided by the project  
2.4 Raising awareness and training  
2.5 The steering and operational groups  
Steering Group  
Operational Group  

## 3. OUTCOMES AND PERSONAL STORIES  
3.1 Achieving a positive outcome  

## 4. BARRIERS TO SELF-DIRECTED SUPPORT  
4.1 The barriers  
4.2 What happened when barriers could not be overcome?  

## 5. COSTS AND BENEFITS OF SDS  
5.1 The costs of SDS  
5.2 The benefits of SDS
5.3 Cost-effectiveness

6. RECOMMENDATIONS

7. CONCLUSION

8. APPENDIX ONE

ALZHEIMER SCOTLAND SELF-DIRECTED SUPPORT PROJECT AYRSHIRE

Terms of Reference for Project Steering Group and Operational Group

Background

The pilot project

Project aims

Project Steering Group
  Membership
  Remit

Operational Group
  Membership
  Remit

APPENDIX 2

Response to Scottish Government’s Self-directed support: A National Strategy for Scotland consultation

Introduction

Dementia

Self-directed support and dementia

Self-Directed Support Strategy consultation

KEY COMMENTS

Move to self-directed support as default position

Managing a direct payment

Better information and improved professional awareness

Eligibility criteria and lack of early intervention

Beyond direct payments- other forms of self-directed support

Hourly rates and outcomes
Providers and the social care market 57
Brokerage 57
Employing PAs 57

RESULTS FROM THE CONSULTATION EVENT 58

Making self-directed support work for people with dementia 58
  Communication & information 58
  Assessment and eligibility 59
  Budgets 60
  Process 61
  Support 62

What does self-directed support mean at the early stages of dementia? 63
What does self-directed support mean at the middle stages of dementia? 63
What does self-directed support mean at the advanced stages of dementia? 64

CONCLUSION 65

APPENDIX 1 - SCRIBE NOTES FROM KILMARNOCK EVENT 67
APPENDIX 2 - QUESTIONNAIRE RESPONSES 77
APPENDIX 3 EVALUATION FORM RESPONSES 78
Foreword

When Alzheimer Scotland started this pilot project we were uncertain as to how much interest in self-directed support there would be amongst people with dementia and their families in Ayrshire, particularly as an alternative to residential care. We were very pleasantly surprised. From day one, to when around seventy people met in Kilmarnock to hear about this project, there has been an impressive level of interest. As the report highlights, for many people this interest has been converted into very creative and highly personalised self-directed support.

We are grateful to the people with dementia and their families who placed their trust in us and in this approach. We are also very grateful to the Scottish Government for funding this work and helping us challenge the commonly-held view that people with dementia and their families would neither want nor benefit from self-directed support. While self-directed support may not be the right option for everyone this project demonstrates that many families see this as a meaningful alternative to services such as residential care. Our view is that self-directed support and the principles underpinning personalisation are an evolution of the human rights of people with dementia and their families. Self-directed support builds on each person’s right to choice, to control, to self determination, to privacy and most importantly to dignity and respect. People who choose this way are not opting out of the system; they are opting into a partnership, a partnership that in our view empowers the person, their family and the front line social work and health professionals. A partnership that can help bring that little bit more creativity to each person’s support and which ensures that the natural supports in a person’s life are fully utilised and the impact of any state support or funding is fully maximised.

Few people would argue with these principles. However we know that in practice there are still many issues to overcome, systemic changes that need to be made to make this a much simpler and straightforward option for people to choose. We are optimistic that the new proposed legislation will transform this.

We are also very grateful to those professionals who have given their full support to this project. Many social work and health colleagues have greatly supported our work and as with any pilot project others have had to be convinced of its merits. This is the nature of pilot projects and we hope that this project will have helped those in doubt of the merits of self-directed support understand its true value.

Alzheimer Scotland will continue to ensure that self-directed support is a real and meaningful option for people with dementia and their families throughout Scotland. This project has strengthened our resolve and we look forward to a future where people with dementia and their families are using self-directed support from the point of diagnosis and throughout their time living with dementia.

Henry Simmons
Chief Executive
Executive summary

1. Introduction

1.1 There are an estimated 82,000 people living with dementia in Scotland. This number is set to double by 2036.

1.2 In 2009 there were approximately 3,017 people in Scotland using self-directed support (SDS), but only 97 were people with dementia, approximately 4 of whom were in Ayrshire.

1.3 Alzheimer Scotland received funding from the Scottish Government in 2009 to run a two year pilot project with the aim to demonstrate that SDS is a practical, cost-effective approach to providing more personalised services which better support both the person with dementia and the carer and family and which allow the person to stay in their own home, when that is what they and their families choose.

1.4 The pilot worked with people with moderate/severe dementia who had been assessed as needing significant levels of support, in some cases 24 hours per day, to remain safe in their own homes or for whom care home admission was being considered.

2. The Ayrshire self-directed support pilot project

2.1 The pilot project set out to work directly with people with dementia and their carers and families to explore options for the care of the person with dementia, maximising natural supports and using purchased services or employing personal assistants; and to work in partnership with social work staff to assist them to develop their practice.

2.2 The project received 69 referrals. 44 people went on to participate. 31 requests for self-directed support were made, of which 23 were successful.

2.3 Two consultation events for people with dementia and their families were held in conjunction with the Scottish Government to comment on the development of the 10 year strategy and proposed Bill on SDS. Over 100 people attended.

2.4 Person centred planning using the PATH tool (Planning Alternative Tomorrows with Hope) was used to support 10 people with dementia and families to think about their future, their wishes, hopes and dreams and to create an action plan to achieve practical and possible solutions personalised to their own circumstances.

2.5 Awareness was raised of SDS among health, social work and carers through information packs, talks, presentations and training.

2.6 Case studies from the pilot have been used to enhance the practice of local professionals and as digital stories in Alzheimer Scotland personalisation training modules and website.
3. Outcomes

3.1 23 individuals received SDS, 21 as a direct payment, one chose for the Council to hold the budget and one chose to use a laundry service which the Council organised.

3.2 Eight people chose to have a mix of traditional services and SDS. Eight people chose to use an agency to provide their support. Seven chose a personal assistant (employed by the person with power of attorney). Three people chose a mix of personal assistants and agency support. One family received permission to employ a family member under exceptional circumstances.

4. Barriers to self-directed support

4.1 A key learning from the pilot project was the many barriers to accessing SDS, many of which were addressed during the pilot. Barriers included:
   - Lack of information to families
   - Difficulties accessing budgets committed to traditional services
   - Lengthy and bureaucratic process to access SDS including the need to undergo further assessments
   - Long delays due to lack of social work staff capacity
   - Lack of alternatives to direct payments
   - Limited flexibility in use of personal budgets
   - Liability for charges not made for some forms of traditional services
   - Difficulty progressing applications through local process
   - Choice of service restricted to approved providers in some cases, limiting access to specialist providers
   - Staff lack of knowledge of SDS processes
   - Delay to process of SDS application before hospital discharge.

5. Costs and benefits of SDS

5.1 The pilot showed that SDS packages underpinned by comprehensive support planning can lead to positive outcomes for people with dementia, their families, local authorities and health boards.

5.2 The average cost of the SDS packages was £208.10 which can be set against the cost of care home fees of £474.16 or of a care home placement which includes nursing care of £550.81 (National Care Home Contract Rates (Scot) 2011). Over a year, this would equate to an average cost saving of £13,835 per person compared with care home fees or £17,820.92 compared with standard nursing care fees.
6. Recommendations

6.1 The key recommendation is that people with dementia and their families should be actively facilitated to consider using SDS both as an alternative to care home admission for the person with dementia and at earlier stages in the journey of dementia, in order to provide the best possible outcomes through shaping their support to fit their lives and to make best use of their natural supports.

6.2 The learning from the pilot project has also led to a number of recommendations to increase and improve the use of SDS:

- Local authorities and health boards should provide further training on SDS to staff to improve understanding of SDS and of their role in supporting people through the process. Alongside this there should be a clear pathway to access SDS for staff.

- Additional training and risk management procedures should be provided to budget holders to overcome concerns about people misappropriating public funds.

- Additional training should be provided to budget holders to overcome concerns about people misusing public funds.

- Staff at senior levels in local authorities and health boards should provide strong leadership within their organisations to champion SDS.

- Local authorities should review their budgets and commissioning practices to ensure SDS is more accessible for people with dementia.

- Local authorities should simplify paperwork and processes to access SDS, and the person with dementia or their attorney should be able to apply for SDS at any time, without the need for further assessments, if they are already in receipt of services and have an up-to-date assessment.

- Each local authority should make information about SDS and their local policies/process and procedures available in a wide range of formats, including on the internet and in leaflet form, which should be available in a range of local resources.

- Independent advice services should be available much earlier in the process and would benefit from being funded on a national level to increase their independence from local authorities who they may have to challenge, which can create a conflict of interests.

- Local authorities should review direct payment rates and the availability of alternative methods of using SDS such as individual service funds.

- Local authorities in conjunction with COSLA, CIPFA and the Scottish Government should review their local charging policies to avoid inequity for people using SDS compared with traditional services.
• Planning and commissioning of services for people with dementia should be more about achieving a good quality of life and should be person and relationship centred rather than task-based

• Discharge planning from hospital should begin from the point of admission unless the person is seriously ill and SDS application processes should be able to continue during a temporary admission to avoid unnecessary delays

• Families should be supported to design crisis management plans.

7. Conclusion

1. The Ayrshire SDS Pilot has shown that self-directed support works for people with dementia.

2. The benefits of SDS, both in terms of people’s wellbeing and of cost-effectiveness, outweigh the challenges.

“With SDS I feel as if my life has come back to me...I have a life again. He (my husband) is out and about he’s meeting people, rekindling friendships – we have something to talk about….things are totally different and it’s absolutely fantastic”¹

(Marlene – wife of a person who has frontal lobe dementia)

¹ http://www.iriss.org.uk/resources/alzheimer-scotland-self-directed-support-and-dementia-scotland-3
1. Introduction

1.1 Background

“Self Directed Support is fundamental to enabling people to fulfil their aspirations and to contribute to society in a variety of roles as active and equal citizens.”
(Shona Robison MSP).

Approximately 82,000 people have dementia in Scotland in 2011. Around 3,500 are under the age of 65. The number of people with dementia in Scotland is expected to rise to 164,000 by 2036.\(^2\) Approximately 40% of people with dementia live in a care home, often because services to help them remain living in the community are no longer suitable.

Most people with dementia would prefer to stay in their own home for as long as possible and many families would like to care for the person at home. The decision to move a person with dementia into a care home is usually difficult, both for the person with dementia and their family, and it is not a decision that is taken lightly.

Families are often adversely affected and may feel guilt and loss; and they lose much of the support they had when caring at home.

Alzheimer Scotland received funding from the Scottish Government in 2009 to run a two year pilot project with the aim to promote the use of SDS to demonstrate that SDS is a practical, cost-effective approach to providing more personalised services which better support both the person with dementia and the carer and family and which allow the person to stay in their own home, when that is what they and their families choose.

The project was launched in May 2009 and based in Troon, Ayrshire, alongside an established Alzheimer Scotland community based service. The project worked in partnership with North, South and East Ayrshire Councils and Ayrshire & Arran Health Board. A full-time project manager and a part-time project worker were employed to deliver the project, which ran from May 2009 to June 2011.

The pilot was established to work with people with dementia who might otherwise face care home admission. It worked with people with moderate/severe dementia who had been assessed as needing significant levels of support, in some cases 24 hours per day, to remain safe in their own homes. For others there had already begun discussions between the families, care managers and hospital discharge teams about the need for long term care solutions or the likelihood of this level of care being required in the near future.

The Mental Welfare Commission Scotland produced a report, Dementia: Decisions for Dignity in 2010. This report stated that “People with dementia are very often discharged from general hospitals to care homes on a permanent basis instead of returning to their own homes. When someone with dementia who was living at home is discharged from hospital, facilitating a return home should be the starting point whenever possible”.\(^3\)

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\(^3\) The Mental Welfare Commission, Dementia: Decisions for Dignity Report
This report describes the work of the pilot, and shares many positive personal stories collected about how people with moderate/severe dementia are using SDS to remain in their own homes, in their own communities and surrounded by their families, friends and loved ones.

The pilot project has successfully demonstrated that SDS has been a valuable approach for families supporting people with dementia, and has also enabled carers to maintain their identity as a husband/wife/son/daughter alongside their role as carer.

1.2 Core values and principles of self-directed support

Fundamental principles

SDS and all public services are subject to Human Rights and Equalities legislation.

The fundamental principles of SDS are choice and control. Choice is evident where people are able to choose how they live their life, where they live and what they do. People have control of their support by determining and executing the who, what, when and how of the provision.

Human rights principles

*Equality and Non-discrimination:* All individuals are equal as human beings and by virtue of the inherent dignity of each human person.

*Participation and Inclusion:* All people have the right to participate in and access information relating to the decision-making processes that affect their lives and well-being.

SDS demonstrates the human rights principles above through:

- **inclusion**

  Everyone, no matter what level of impairment, is capable of exercising some choice and control in their living, with or without that choice and control being supported by others

- **dignity**

  Everyone is treated with dignity at work, at home and in the community

- **equality**

  Everyone is an equal citizen of the state and has the right to live life as fully as they can, to be free from discrimination, and to be safeguarded and protected.

The Scottish Government proposes to introduce a Self-directed Support Bill to the Scottish Parliament, and the Bill will include guiding principles. Should a Self-Directed Support Act be passed by the Scottish Parliament, implementation of this strategy will be guided by the principles within it.
Social care research has shown that the values that need to be sustained in any reconfiguration of social services are those which have a consensus among stakeholders.

Core values

Successful implementation of this policy depends on a clear values framework that is commonly understood and that reflects a co-production approach. The operation in practice of these values needs to be determined by the end user of SDS. As such, a final values framework needs to be developed to inform the implementation action plan and the work that flows from it. The following values are considered to apply to the overarching principles and are examples of what might be included in the framework to be developed under Recommendation 1:

- **respect**
  
  Everyone is treated with respect.

- **fairness**
  
  Everyone is provided with unbiased information about the choices available to them; and is treated in a manner which befits and benefits their individual circumstances. Fairness is in terms of the individual, not the group or society at large.

- **independence**
  
  Everyone is supported to maximise their aspirations and potential.

  Support focuses on the prevention of increasing dependence and enablement, or re-ablement.

- **freedom**
  
  Everyone is supported to participate freely in all aspects of society, in the same way as other citizens.

- **safety**
  
  Everyone is supported to feel safe and secure in all aspects of life, including health and wellbeing; to enjoy safety but not be over-protected; and to be free from exploitation and abuse.

1.3 Self-directed support in Scotland

SDS provides a range of options to allow an individual to arrange some or all of his/her care and support instead of receiving directly-provided services from their local authority social work or housing department.

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4 Scottish Government, Self-directed Support: A National Strategy for Scotland
SDS is for people who would like more flexibility, choice and control over their care and support so that they can live at home more independently. It is not the name of a particular type of service but a way to shape personalised care and support that provide improved outcomes.

Choosing SDS allows an individual to direct his/her own care and support. It gives individuals greater control in deciding how the money available to them is spent on the support they need, instead of receiving council services. Individuals can also choose a mixed arrangement allowing them to organise some of their own support and also receive some council-arranged services.\textsuperscript{5}

SDS in the form of direct payments has been available to disabled people aged 18-64 since April 1997 and to disabled people aged 65 and over since July 2000. From 1 June 2003 it became a duty for local authorities to offer direct payments in place of providing services to all eligible disabled people.\textsuperscript{6}

The Scottish Government issued statutory guidance in 2007\textsuperscript{7} which detailed specific tasks for local authorities to fund. Not all local authorities are currently in compliance with the guidance and in particular the need to supply direct payments on a gross basis.

The Scottish Government and COSLA have produced a 10 year strategy to promote the future development of SDS and make this a mainstream approach to the future delivery of care and support in Scotland. It contains 26 recommendations to move this agenda forward.

The Scottish Government also plan to present a new Bill to Parliament – The Self Directed Support (Scotland) Bill - in this parliamentary term. This will provide a formal legal basis for SDS in Scotland.

\section*{1.4 Self-directed support and people with dementia}

SDS has historically been rarely used by people with dementia. There were approximately 68,334 people in Scotland receiving homecare support in March 2009. 80\% of homecare clients were over 65 years of age and approximately 3,725 were people with dementia.

In 2009 there were approximately 3,017\textsuperscript{8} people using SDS, of whom only 97\textsuperscript{9} (3.2\%) were people with dementia. In May 2009, at the start of the pilot project, there were approximately 4 people with dementia in Ayrshire using SDS.

\begin{footnotesize}
\begin{enumerate}
\item \url{www.selfdirectedsupportscotland.org.uk/directing-your-own-support}
\item \url{www.scotland.gov.uk/Publications/2010/01/25130907/1}
\item \url{http://www.scotland.gov.uk/Publications/2007/07/04093127/0}
\item \url{http://www.scotland.gov.uk/Publications/2010/01/25130907/1}
\item \url{http://www.scotland.gov.uk/Publications/2010/09/27093422/0}
\end{enumerate}
\end{footnotesize}
In 2011 there were approximately 4,392 people using SDS in Scotland and the number of people with dementia using SDS had increased to 151,770 (3.4%). This is still low compared to other groups of people who use SDS. People with physical disabilities are the most likely group of people to use SDS with 1,770,11 (40.3%) of all direct payments being made to this group.

People with dementia also have, on average, lower packages of support compared with other groups of people who use services, with over 46% of all SDS funding allocated to people with physical disabilities and only 2.8% of SDS funding allocated to people with dementia in 2011.

### 1.5 The journey to long term residential/nursing care

People with dementia and their families often experience a lack of choice and access to flexible, personalised support services before a decision to move the person to a care home is made. Some carers of the pilot’s participants had other responsibilities and commitments such as work and children. Others had given up a considerable part of their own life including employment, religious activities, seeing friends, going to activities, such as book clubs, choirs and other social activities. One participant had to give up counselling sessions in order to care for a family member with dementia.

Families were often in crisis at the point of referral to the project. Some people reported being on medication for stress. Others expressed feelings of exhaustion and even thoughts of suicide.

For many of the carers traditional forms of service provision failed to provide enough flexibility to maintain their caring role alongside their other commitments. SDS however enabled them to use a similar level of formal support but re-configured in a more personalised way to enable them to continue to care whilst managing their other commitments.

Maintaining the person with dementia at home with a more flexible package of support was often a considerably cheaper cost than moving the person into a care home. We have provided a selection of case studies with cost comparisons in Section 3 of this report.

For some people day care/respite care in a building based facility is not appropriate or they do not wish to use this type of service.

Respite services in the Ayrshire area are mainly pre-purchased in residential care/nursing homes. Many couples on the pilot did not use building based respite services, unless in a crisis, as it was their wish to remain together for as long as possible and not to be separated. However this meant that the carer often then went without any respite and they felt this affected their ability to manage care on a long term basis.

SDS offered pilot participants an alternative method of organising their care that is more tailored to their individual needs and preferences and enabled them to benefit from more flexible respite that did not require separation. It created better outcomes for the person with dementia and their families.

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Assessments for long term care sometimes fail to comprehensively detail and record the level of need the individual being assessed has but recorded the outcome of the assessment as a recommendation as requiring care in a care home. This could be the case even when the person being assessed has not been in receipt of formal care services prior to the assessment.
2 The Ayrshire self-directed support pilot project

2.1 Project activities

The pilot project set out to:

- Work directly with individual people with dementia and their carers and families to assist them to explore options for the care of the person with dementia, maximising natural supports and using purchased services or employing personal assistants

- Assist families to consider the full range of funding options including direct payments or individualised budgets, where these can be negotiated, and to set up mechanisms for managing any payments on behalf of the person with dementia; link them into organisations supporting employers of personal assistants where appropriate

- Work in partnership with social work staff to assist them to develop their practice in order to offer SDS to more people with dementia

- Work with organisations supporting the employment of personal assistants to ensure that they are dementia-friendly and to ensure that personal assistants can access dementia training

- Work with the Alzheimer Scotland Dementia Helpline to raise awareness of SDS and to provide information

- Collect success stories and disseminate these through the Alzheimer Scotland website and through contributions to publications, conferences and publish a report.

The project received 69 referrals over the two years of the pilot. 30 were men and 39 women. 44 people went on to participate in the pilot. 31 requests for SDS were made of which 23 were successful. Of the eight others, four people died during the application process. A further four people were admitted to care homes (two following an emergency admission to hospital).

<table>
<thead>
<tr>
<th>Council Area</th>
<th>North Ayrshire</th>
<th>South Ayrshire</th>
<th>East Ayrshire</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of referrals</td>
<td>19</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>No. of SDS packages</td>
<td>7</td>
<td>6</td>
<td>8</td>
</tr>
</tbody>
</table>

Thirteen people participated in the pilot but did not request SDS. This was for a variety of reasons which included a change of diagnosis, the family not ready to proceed at the time, admittance to long term residential care, accepting more traditional services provided by the council or becoming too ill to continue.

Families were offered support and assistance at a level suitable for their individual needs. For some this was low level support to provide information about SDS and how to access it. For many others there was more intensive one-to-one support throughout the whole process, including attending meetings, organising person-centred planning sessions and multiple home visits, phone calls and emails.
Project staff supported families with a range of issues, some in relation to dementia, and others more general issues that families faced such as housing, adaptations, benefits, maintaining relationships, signposting to other resources and coping with stress of caring.

During the pilot the project staff, in conjunction with the Scottish Government, held two consultation events for people with dementia and their families to comment on the development of the ten year strategy and proposed Bill on SDS. Over 100 people attended these events which were also attended by members of the Scottish Government and Local Authority staff.
Person centred planning is an outcome-focused tool used to support people to think about their future, their wishes, hopes and dreams and to create an action plan to achieve practical and possible solutions personalised to their own circumstances.

Eleven people with dementia or their main carers accepted the offer to participate in a person-centred planning session using the PATH tool (Planning Alternative Tomorrows with Hope).
One person’s session did not proceed as they had an emergency hospital admission and sadly passed away. These sessions were usually offered when there were complex issues to overcome; this included sessions with two families where both their mother and father had dementia.

Planning sessions normally lasted between two and four hours, depending on the individual, the participants and the complexity of the issues that arose.

Two trained facilitators guided the group through the various steps of the process but it was not their role to influence the process or make decisions. Person-centred planning is not an assessment tool and is not about getting or receiving social work services.

The outcomes from the sessions were positive and as a result six people chose to request self-directed support. One person decided to move house and for many others it was about building networks of support. People reported feeling more hopeful about the future and felt they had a plan to work towards in partnership with others.

Quote from Peter, carer for his wife who has Alzheimer’s, talking about his experience of having a person centred plan done “What a cathartic experience that was…”.

### 2.3 Other support provided by the project

Project staff attended review, assessment and hospital discharge meetings, when requested to do so by the individual or their family.

Project staff supported pilot participants to consider how they would like to be supported and what this would look like for them; would they prefer to use the services of a local agency or become an employer and recruit their own personal assistants. Staff also supported people to consider what skills, characteristics, experience or resources they needed from support staff and assisted some people to find the right person for them.

All pilot participants were referred to the local independent support service, Ayrshire Independent Living Network (AILN), which is directly funded by the three local authorities. Joint visits were arranged with AILN staff to support families through the initial steps. AILN offered a range of support services to people using direct payments, including assistance with recruitment of personal assistants, job descriptions, employment contracts, payroll and employers insurance. Participants were also given information about the Scottish Personal Assistants Network (SPEAN) when they were planning to become an employer. The membership cost of SPEAN is not included in direct payments allocated.

Pilot participants were informed about dementia specific training available for staff. AILN arranges a range of training for personal assistants and can tailor this to the individual need.

The majority of social work staff we worked alongside did not have practical experience of going through the process of delivering SDS. There was confusion about how SDS could be used. To support both staff and participants, we organised joint visits to pilot participants with individual social work staff to support their practice, when the social worker was willing to accept our presence.
2.4 Raising awareness and training

Very early in the pilot it became a priority for the staff to improve upon low levels of awareness of SDS amongst health, social work and carers. Information packs were developed which included a range of materials:

- A Guide to Direct Payments – Scottish Government
- Self-Directed Support in Scotland – Scottish Government DVD
- Taking Charge – Alzheimer Scotland
- Ayrshire Independent Living Network (AILN) - information sheet
- Self-Directed Support, project leaflet - Alzheimer Scotland

Only South Ayrshire Council made available specific local information leaflets. These were included in the packs for participants in South Ayrshire, as although this local leaflet was already available, awareness of this was not wide among frontline social work staff.

Talks, presentations and training were also delivered to social work and health staff, as well as to carers’ groups.

Presentations, talks and training were delivered to staff in each of the three local authority areas. These opportunities were used to share a range of resources with staff that they could use to enhance their awareness and practice.

The project manager facilitated a session with Alzheimer Scotland Dementia Helpline volunteers to improve their awareness of SDS and provide a range of resources that would enable them to offer low level support to enquirers.

The project staff, along with Alzheimer Scotland IT department, developed a specific area of the Alzheimer Scotland website about the work of the project. This included details of forthcoming events and reports submitted to the Scottish Government, along with feedback from the two consultations events that were facilitated.

Digital stories have been produced using case studies from the pilot and are being used to develop personalisation modules which will be delivered across Scotland by Alzheimer Scotland. The digital stories will also be available on the Alzheimer Scotland website. Case studies from the pilot have been used to enhance the practice of local social workers, health staff and social care staff.

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12
- 20 social care staff received training on personalisation and dementia using self-directed support
- Training session for 13 Alzheimer Scotland, Helpline Volunteers
- 5,000 leaflets produced and circulated to Social Work, Health and local community resources
- Presentations given to two teams in East Ayrshire, all senior staff and 1 Locality Team in South Ayrshire, two Community Mental Health Teams (Kilmarnock & Largs)
- Talks given at four carers groups and visits to two dementia café events
2.5 The steering and operational groups

**Steering Group**

The steering group was set up at the inception of the pilot. Membership was agreed with the local authorities, health board and Alzheimer Scotland. The group met quarterly and supported the development of the pilot and offered support to the project staff to overcome any difficulties that were arising as new participants were making their way through the process of applying for self-directed support.

It was initially hoped that the local authorities and the health board would agree to provide upfront indicative budgets. This objective was not achieved but it was agreed each circumstance would be looked at on a case by case basis. Some participants challenged the budget offered as they did not feel it met all of their needs. Some carers felt they were not receiving enough formal services to compliment the extensive caring commitments they had made, especially when requesting overnight care support.

The steering group were key partners in the production of reports produced for the Scottish Government. There was commitment from all partners to accept that the pilot was there to uncover the difficulties people with dementia and their families faced in trying to access SDS so local and national policies and procedures could be adapted to enable more people to use these resources.

See appendix 1 for the terms of reference and membership of the steering and operational groups.

**Operational Group**

The operational group was established following the first meeting of the steering group. Once again our partners were very generous in their support and each offered two members of staff, usually a senior social worker and a member of the direct payment team, to attend the group.

This group was key to connecting the project staff to local resources and identifying opportunities to promote the pilot to local authority and health board staff.

The group supported the project staff to deal with procedural matters which caused delays for pilot participants trying to access SDS. This was also a useful forum to share areas of good practice.

At the end of the first year the steering and operational groups were merged as the project staff had a steady stream of referrals and had established a good network of contacts in each area.
3. Outcomes and personal stories

3.1 Achieving a positive outcome

While the process to accessing SDS was often lengthy and bureaucratic the outcomes achieved were beyond expectations.

Twenty-three individuals received SDS. Twenty-one took this in the form of a direct payment. One person chose to re-organise their support but for the Council to hold the budget. One person chose to use a laundry service which the Council organised with the provider.

Eight people chose to have a mix of traditional services and SDS. Eight people chose to use an agency to provide their support. Seven chose a personal assistant (employed by the person with power of attorney). Three people chose a mix of personal assistants and agency support. One family received permission to employ a family member under exceptional circumstances.

The planning and support process facilitated by pilot staff was not focused on receiving support services but on achieving positive outcomes for the families. This meant providing support with all areas of their lives which included housing, income maximisation, family relationships, community connections and achieving the best quality of life possible.

In the last few months of the pilot a budget became available from Shared Care Scotland to purchase flexible respite service. At the time of writing this report one family had been successful in applying for this funding for a trip to York in July 2011. This is the first trip this couple have taken together for several years. Another family applied to the fund to have a respite break in Arran accompanied by their personal assistant. There has also been an application for funding to arrange a visit to the Edinburgh Military Tattoo. These are all examples of creative solutions which can provide better outcomes for individuals, as well as cost effective alternatives to traditional models of respite care.

The following personal stories from people participating in the pilot\(^{13}\) demonstrate how SDS can and does make a difference to the care, support and quality of life for people with dementia and their families.

\(^{13}\) Names have been changed or are used with permission
Example of creative support

Mrs W lived at home with her daughter and family. She had attended a day care facility five days per week but was becoming too frail to continue. Her daughter did not want carers coming in and out of the family home but was struggling to cope with the demands of caring. Mrs W required support with continence and project staff suggested a way of reducing strain might be to request a laundry service. This was agreed and has made a remarkable difference for Mrs W and for her daughter, who can now spend the time she previously spent doing laundry, taking her mum to see friends and family or going out for lunch.

Example of achieving positive outcome using personal assistants and agency support

Kenny and Marlene live in a sheltered housing complex (specially designed for people with dementia) in Ayr. Both Kenny and Marlene were unhappy with where they lived. Marlene felt she had no-one her own age around and Kenny felt he did not have any privacy. Marlene was struggling to cope with the challenges of caring for Kenny, who has dementia, and this was affecting her health and well-being and their relationship was reaching breaking point. Marlene had given up most of her social connections and her life focused around caring for Kenny.

Marlene has power of attorney for Kenny. With support from the pilot, she applied for a direct payment and was initially offered five hours of support per week. Following a person-centred planning session this offer was discussed with the social worker and increased to 25 hours per week (18 hours as an alternative to day care, seven hours for personal care).

Marlene and Kenny knew a local agency worker who had known Kenny for many years and had all the qualities needed to be a personal assistant for Kenny. He began working with Kenny two days per week. Marlene also recruited a second personal assistant who she employed on behalf of Kenny. Now between the workers they provide the type of support Marlene and Kenny are both very happy with. Kenny is often out and about and is re-connecting with old friends and places he enjoys being and Marlene has managed to re-connect with friends and family. As a result Marlene feels she now has a better relationship with Kenny. They have more to talk about and Marlene feels more able to cope. Marlene and Kenny have just recently received the keys to their new home and they hope to move in soon.

Costs
\[
\begin{align*}
13 \times £10.50 &= £136.50 \text{ (Agency rate)} \\
12 \times £9.50 &= £114.00 \text{ (Personal assistant rate)} \\
\text{Total cost} &= £250.50 \text{ per week.}
\end{align*}
\]
Example of lowest cost

Mrs A has dementia and lives alone. Her son and daughter-in-law lived nearby and popped in to visit, provide meals and support to attend church on a Sunday. Mrs A had a fall and ended up in hospital for a number of weeks. The recommendation from the hospital was long term residential care. Mrs A wanted to go home and her family supported this decision. The main risk highlighted was Mrs A’s wish to visit the local shops on a daily basis and how vulnerable she would be in doing so. Traditional task-based homecare services were not available to accompany Mrs A to the shop and Mrs A would be unlikely to accept support.

Mrs A was discharged with 14 hours of traditional homecare services to assist with meals and personal care. Mrs A refused to allow homecare staff into her home and was confused by the range of different people coming to her door. This increased Mrs A’s levels of agitation. The service was reduced to 7 hours per week.

With help from the pilot the family applied for a direct payment and were given permission to employ a member of the family to provide the support to Mrs A. This reduced the confusion Mrs A had. Mrs A was willing to accept the support from a family member and there was someone on hand to support Mrs A to visit the local shop safely.

Total cost 7 x £9.50 = £67.50 per week.

Example of good practice and using person-centred planning

Mrs N has severe dementia and other underlying health problems. Mrs N’s husband was providing 24/7 care for his wife but as a result his children were becoming concerned about his health and well being.

The Care Manager and Community Psychiatric Nurse agreed to participate in a person-centred planning session which was facilitated by the project staff. The outcomes from the planning session were included in the care plan part of which was to have SDS. The assessed needs were agreed and within 4 weeks Mr N had been notified of how much SDS support would be available.

Mr N recruited a personal assistant who had known his wife for many years. Mrs N remained at home for a further 8 months. Following an admission to hospital for assessment of her medication it was decided Mrs N now required long term care in a care home.

Total cost 21 hrs x £10.52 = £220.92 per week.
Example of a younger person’s journey

Mrs A is 54 years old and has dementia. She was living at home with her husband and daughter. Mrs A requested a direct payment in 2008 but had been unable to secure agreement to this with the assistance of the project a direct payment was agreed in June 2009. Mrs A was granted 20 hours of support as an alternative to traditional homecare services as traditional services were not working for either Mrs A or her family. Mrs A’s family felt a direct payment would enable them to personalise the allocated care hours more to Mrs A’s needs and complement the support Mr A, family and friends were able to provide.

A care plan was prepared by the social worker and family for Mrs A that would enable a reduction of carers, reduce duplication of support and provide better outcomes for Mrs A and her family whilst ensuring other informal supports were maximised. Alzheimer Scotland\(^\text{14}\) was the chosen provider and two members of staff were recruited and trained to work specifically with Mrs A, with a third member of the existing team acting as a back-up support. Staff supported Mrs A to re-connect with old friends and colleagues and focused their support on Mrs A’s wants, needs, wishes, preferences, passions and things that were important to Mrs A. Mr A as the main carer was fully included in all decisions relating to the care of his wife. As Mrs A’s condition continued to deteriorate rapidly her support was increased to 27 and later 32 hours per week, all provided via a direct payment. A further increase to 40 hours was requested but refused. In October 2009 Mrs A attended her daughter’s wedding, an experience the whole family had worried she would miss due to her dementia progressing rapidly and her fear of being in large crowds. Mrs A remained living in her own home for an additional 6 months. Sadly she was detained under the Mental Health Care and Treatment (Scotland) Act 2003 and subsequently moved to a long-term care establishment.

Costs

\[
\begin{align*}
20 \text{ hours} & \times \£10.46 = \£209.20 \\
27 \text{ hours} & \times \£10.46 = \£282.42 \\
32 \text{ hours} & \times \£10.26 = \£334.72
\end{align*}
\]

\(^{14}\) Alzheimer Scotland charges were higher than the direct payment rate of £10.46 per hour. Mrs A’s family could have made a case to the care manager to increase the direct payment rate to employ a specialist service but they chose not to.

The direct payment did not cover any travel costs incurred while supporting Mrs A. Mr A agreed to fund this privately using their own resources as Mrs A enjoyed visiting different places and this could not be done safely using public transport.
**Example of alternative to direct payment**

Mr D was in his 90s and lived at home with his daughter Heather in a semi-rural location. His daughter was finding it difficult to maintain her employment at a local hospital working several nights per week whilst caring for her Dad who required 24/7 support because of his dementia. Mr D attended a local day care service twice a week but he would often refuse to go or in bad weather conditions the transport would not be able to reach Mr D’s home. This meant Heather would have to call on a member of the family to come and care for Mr D while she got some sleep following a night shift.

Mr D’s other daughter or granddaughter would care for him while Heather worked nightshift. Heather reduced her working hours to care for her Father. Mr D also received daily visits from the homecare service. Heather felt the day care provision was not meeting either of their needs and requested a direct payment to enable more personalised care to be organised. A compromise was agreed and they accepted a three hour block of homecare services per day. This helped the family to balance their caring, work and family responsibilities and enabled Heather to have a few hours’ sleep following her nightshift.

**Example of hospital admission to home**

Anna was admitted to hospital following a fall in September 2009. Prior to this Anna was not known to services. She was diagnosed with dementia and an assessment was carried out which stated Anna needed care in a care home and was not safe to return home. Anna’s family advocated strongly for her to go home with a package of support.

Anna was discharged from hospital and her family provided round the clock support supplemented by four visits per day from homecare services. This arrangement was not sustainable and the pilot supported the family to request SDS. A package which consisted of twenty-eight hours via a direct payment, three days of traditional day care provision and six weeks traditional respite was agreed.

Anna’s family supplemented this package with Anna’s attendance allowance and other personal finances. Anna’s family recruited three personal assistants who provided support which complemented the natural support Anna had from friends and family. Anna continues to live at home two years later and they are only now considering the need for Anna to move to a care home.

Direct Payment 28 hours @ £9.50 = £266
3 days at day care @ £30 per day = £90
6 weeks of respite care @ £424 = £48.92
Total Cost = £404.92
Example of using a mix of services

Margaret is married and is mum to two grown up sons. Margaret writes poetry and enjoys singing, meeting, chatting to people, going to church and seeing friends and family.

When Margaret was diagnosed with dementia she stopped leaving her house and would either stay in bed all day or sit in her chair all day/night and gave up all the things she had once enjoyed. Margaret stopped eating properly or taking care of herself; she was very low in mood. Her son visited every day but he was becoming increasingly concerned about his mum’s health and wellbeing.

Following an assessment Margaret started going to day care three times a week. Margaret is now writing poetry again and shares this with the other people at day care. Margaret also enjoys playing musical bingo, domino’s and going to the bi-weekly cheese and wine event at the day centre. Margaret likes the pampering sessions available and especially having her hair and nails done. Margaret is now at a healthy weight and her son attributes this to Margaret being used to now eating in social situations again at the day centre.

Margaret’s son requested a direct payment instead of traditional respite and homecare services. Having flexible respite at home which is funded via SDS, combined with the support from the day centre, has allowed Margaret to now live a full and active life. Margaret has now re-connected with friends, her church and her community. She is now planning a trip to Arran this summer. Margaret’s son has now requested a direct payment for his father, who has a physical disability, for his personal care support needs.
4. Barriers to self-directed support

A key learning from the pilot project was the many barriers to accessing SDS. In most instances, with the support of our link officers in each local council, the pilot project was able to support people through the difficulties they faced, and during the course of the pilot, some of the barriers were addressed by local authorities and health.

The first successful applicant to receive SDS got a direct payment one year after first requesting self-directed support. Unfortunately this was not an uncommon timescale which caused frustration and stress for families who were already dealing with a range of complex and emotional issues as their loved one’s health and abilities declined.

While referrals were steady, achieving outcomes was in most cases a long and difficult process. Many families felt they had needless additional assessments and meetings that made no discernable difference to the care their loved one received.

4.1 The barriers

- **Information**
  
  Many families were unaware SDS even existed. They said they had never been informed about it or offered a choice to have it, despite in most cases being a carer for five or more years and being in receipt of formal care services.

  “I look after my Dad and nothing like this (SDS) has ever been mentioned”

  “It’s been 10 years (of caring for husband with dementia) and I’m just finding out about this (SDS) now.”

  (Quotes from people who attended a consultation event on 30th March 2010)

- **Budgets**

  Currently and throughout the duration of the pilot there was no specific budget line for SDS available with any of the three councils. Respite and day care budgets were in the main spent on building based support services. Personal care budgets were slightly more flexible but there was considerable amounts spent on commissioning large scale tenders for homecare services. This created difficulties when people were trying to access budgets for services that were fully committed elsewhere. However the councils were able to access resources to fund the direct payments requested from the limited flexible budgets they had available.

  “It’s about support that keeps people doing what they have always done, not just the basic of staying alive – and keeps carers having a life too” (family carer)

- **Processes and assessment**

  The current process to access SDS is lengthy and bureaucratic to navigate. It is further complicated by the need to undergo further assessments. In some cases families had to have many meetings to discuss their wishes to access SDS and this caused unnecessary delays. In their opinion people felt they were being stalled and “…talked out of it [SDS]” (family carer). They had to remain steadfast in their wish to have SDS. Payments were also delayed while personal assistants underwent PVG checks.
when families could have used their budgets to enlist the support of a support agency in the interim. Social workers’ assessments were sometimes queried once given to a more senior member of staff for resource allocation and despite the people the pilot worked with being at a stage where they were likely to need residential care and in some cases had already had recommendations for residential care, some people were left with packages of community-based support which were insufficient, in their opinion, to meet their needs.

“They’re trying to fit people’s lives into the system” (family carer).

- **Delays due to staff capacity**
  Some people waited over six months to have their assessment of need completed. This was usually down to the demands placed on individual social workers; planned meetings were, on occasions, cancelled and rescheduled to accommodate crises elsewhere. Sick leave and holidays also contributed to delays in having assessments completed and in one occasion the system set up to assess new clients was not operated to the stated policy and led to a delay of over two months in appointing a social worker to assess.

- **Alternatives to direct payments**
  All three local councils are able to offer SDS in the form of a direct payment but other alternatives such as individual service funds are not yet available. This therefore excludes people who do not have the capacity to manage the budget for themselves and who do not have a financial power of attorney or a guardian in place to manage the budget on their behalf.

- **Flexibility, choice and control**
  In South Ayrshire direct payments were only initially available instead of personal care. Other budgets were fully spent purchasing building based day care and respite beds in bulk. In East Ayrshire SDS was offered on a like-for-like basis. Under this policy individuals were constrained on how they could use their budget. For example one woman who did not wish to attend day care wanted to use her budget to arrange support to go swimming and attend dance classes. As these activities were not available at day care facilities there were concerns raised about the appropriate use of the budget allocated, following discussion with the Council agreement was reached to use the budget in a more flexible, personalised manner.

Due to the progressive nature of dementia and the increasing need for one-to-one support, services which operate in a group setting such as day care, may not continue to be suitable to support the person with dementia appropriately. Residential respite is not always seen as a positive choice by people and their families where the person would still be able to use mainstream holidays or short breaks with family/friends, with support to get the benefits of respite without being separated from their routine or loved ones. Some pilot participants were left with little or no choice of support when day care became inappropriate or respite was needed and this increased the burden of responsibility put on the informal support networks. Personal budgets could help to ensure that the money is more easily transferred with the person to home/community based one-to-one care in these instances.
• **Charging**
  Some people who moved from using traditional services to using SDS were subject to increased charges when transferring over. An example is in many cases day care was provided free or at very low cost and no financial assessment would be carried out, however if a direct payment was requested as an alternative to day care a financial assessment was carried out and charges applied when above the relevant thresholds. Pilot participants felt this was unfair and inequitable. This also put some people off choosing SDS. In one case (not part of the pilot), involving a transfer from two days of day care for a younger person (who was not enjoying day care) to direct payment, a charge in excess of £80 per week was applied. As a result the decision was made by the family to keep the person at the day care.

• **Power and control**
  Despite being clear about their wish to access SDS, some pilot participants’ applications were not processed. On some occasions project staff were advised that the participants had changed their minds despite participants insisting that this was not the case. Project staff were given clear parameters to work within and there was some debate about project staff being given permission to facilitate-person centred plans for pilot participants. Some council’s felt this was a care management role. Following discussion with the steering group members it was agreed that the social worker would remain the lead person and key contact but that the person-centred plans could be facilitated by project staff when deemed to be appropriate.

• **Approved provider lists (APL)**
  Some social work staff informed pilot participants that they could only use their direct payment to purchase services from providers on their approved providers list. This limits the choice and control over who provides services and undermines the principles of SDS. In particular it operated to restrict some participants from choosing a specialist provider.

• **Lack of staff knowledge**
  “It shouldn’t be a postcode lottery or depend on who you speak to. You should be able to go to any professional involved in care and they could tell you (about SDS) – there’s no room for anomalies in health care.” (family carer)

Not all staff with care management responsibilities are fully aware of how SDS works in their local area and how to process an application for SDS. Not all Alzheimer Scotland staff are aware of SDS and how it works. Despite having a legal duty to inform potential recipients about their rights to direct payments and a tick box reminder on the single shared assessment paperwork, the pilot found that many staff still do not advise people of this option. Other staff informed people of their rights to direct payments but the information was sometimes patchy, incorrect or come from a negative perspective.

• **Living outwith the area of normal residence**
  When people move to a different Council area there can be issues in relation to which Council pays for their care. This matter was raised on a couple of occasions and each time there were added complications for the family members involved in trying to access funding. An example was a father who lived in South Ayrshire who went to live with his daughter in England rather than move to a care home. He kept his
property in South Ayrshire but required formal support services to be delivered in England. The project supported the family to access a direct payment which was backdated to the date when the direct payment was initially requested following an assessment of need. The family continue to have issues in relation to the amount of direct payment which has been received which the Council capped at the cost of a care home.

- **Hospital discharge planning**  
  Several pilot participants were in hospital when referred to the pilot. One had already begun the process of applying for a direct payment and had been assessed at home. This process was put on hold while the person was in hospital. The family’s preferred option would have been for the process to continue while the person was in hospital so that arrangements could be in place by the time of discharge. As the process to access SDS is lengthy the sooner the process is started the better the outcomes for the individual concerned. If upon discharge the person would require additional support it would be easier to increase the budget and negotiate additional hours with personal assistants or agencies rather than starting from the beginning and having to make do with interim arrangements.
4.2 What happened when barriers could not be overcome?

The following case studies are examples of our failure to support families to achieve SDS.

Ronnie and Helen

Ronnie had dementia for 10 years before his wife Helen (his main carer) requested SDS in the form of a direct payment in May 2009. Ronnie had an occupational therapist as his care manager but occupational therapists were not able to process an application for SDS in East Ayrshire, so the case was transferred to social work.

A worker was appointed several weeks later and arranged to visit Ronnie and Helen at home. Helen stated the social worker tried to talk them out of applying for SDS but Helen remained committed to the process. The worker was unsure of what could and could not be processed as SDS and was unable to provide clear information to Helen. Project staff attempted to assist the worker to process the application for SDS but were informed that Ronnie and Helen did not want SDS. However this was checked with Helen and she said they did wish to proceed. This was communicated to the social worker and Ronnie and Helen were referred to Ayrshire Independent Living Network.

Several further meetings with Ronnie, Helen and the social worker happened and a meeting was arranged with a senior member of social work staff. Helen remained steadfast in her wish to have SDS but was beginning to think it might never happen. During this time Ronnie’s health began to deteriorate significantly and within 6 months he had been admitted to hospital.

Upon discharge Helen again requested SDS but accepted traditional homecare services in the interim. Ronnie’s place at day care broke down and no alternative form of support was put in place. Helen opened a bank account in preparation for receiving SDS but it never materialised. Ronnie was admitted to hospital again and sadly passed away in June 2010.

Helen agreed to have her case study recorded and shared with the local authority to use as a training resource. This happened later in 2010.
The Lennox Family

Mrs Lennox, “Granny”, lived in her own home with informal support from her family, friends and neighbours.

Her family were determined that Granny would not go into a care home but knew that they could not sustain the level of support that she was going to need to stay at home without formal services. Through the project they requested an assessment of Granny’s needs in January 2010 and stated their interest in SDS. A social worker was allocated in April 2010 but was on holiday till May 2010. Mr Ian Lennox (son) called social work and was advised that there would need to be at least two assessment visits and then it would take months to process the application for SDS, after which they would be put on a waiting list to receive a direct payment.

The social worker arranged an assessment visit with the family for the 21st May 2010. The worker failed to turn up or cancel the visit. The family were disheartened by the level of support they had received. In July 2010 Granny became very unwell and stopped eating and drinking. The family wanted a PATH done by the Project to ensure Granny had a quality of life in the final months of her life. The link officer advised this would not be appropriate as care planning and assessment was the responsibility of the social worker. A new social worker was allocated to the case. Granny’s health deteriorated further and the rapid response team and district nurse were called upon to assist the family. Mr Lennox moved into his mother’s home and the rest of the family rallied round to provide Mr Lennox with respite. During this time the family continued to express their wish to have SDS. Several emails were sent to social work by them and by project staff. Weeks later a response was received to advise that the family had neither requested SDS or wished to have SDS. The family responded reiterating their ongoing wish to have SDS. The worker appointed to the case was a social work assistant and could not complete all the paperwork necessary to apply for SDS so the case was passed to another colleague to carry out the financial assessment in August 2010. Granny sadly passed away at home in September 2010.
Marie and Mike

Marie was an artist, animal lover, mother, wife, sister and friend who lived at home in a semi-rural village in Ayrshire with her husband Mike and two grown up children. There had been concerns raised about Marie’s family’s ability to care appropriately for Marie because of her needs relating to her dementia and a case conference was called in June 2010. Marie was not invited to attend this meeting and an independent representative was not appointed. The outcome of the meeting was a recommendation for Marie to be moved to a care home. Marie was able to articulate her wish to remain living in her own home with her family and surrounded by her animals and art work. Marie expressed a threat to her own life if she was moved from her home against her wishes. The local authority stated they were going to apply for guardianship despite Marie’s wishes and those of her family. Marie’s GP stated that Marie’s past and present wish was to remain in her own home.

The project staff and local dementia advisor worked with Marie and her family to produce a person-centred plan to focus upon the life Marie wished to have and to address the risks the social work department had identified. Marie’s husband requested SDS in writing (October 2010) as Marie did not like day care or going into residential care for respite which limited the formal support they could call upon to improve Marie’s care. No progress was made to achieving SDS for Marie but several things were achieved that improved Marie’s quality of life for the last few months of her life. Marie’s artwork was reproduced and used as the Lord Provost’s Christmas Card 2010. Marie passed away quietly at home in February 2011.
5. Costs and benefits of SDS

5.1 The costs of SDS

The experience of the project showed clearly that there are costs to accessing SDS. SDS takes time to access, requires the recipient to complete additional paperwork and when choosing to become an employer take on the responsibilities that come with this choice which includes complying with complex employment law.

Choosing SDS currently is a complex matter, further complicated by the lack of understanding of the concept among professionals and the public alike and by the confusion in language between direct payments and SDS. SDS as a concept has no current legal basis and all current legislation relates to direct payments. The Social Care (Self-Directed Support) Bill if passed by the Scottish Parliament, should help to define and clarify what is meant by SDS.

For care management staff SDS represents a shift in culture, power, relationships and practice. Being an advocate for SDS could also potentially put care management staff in conflict with budget holders who do not have the resources to finance and maintain two separate systems of providing social care.

5.2 The benefits of SDS

The key finding of the pilot project has been the extent to which SDS packages which are underpinned by comprehensive support planning can lead to positive outcomes for people with dementia, their families, local authorities and health boards.

People with dementia using SDS through the pilot benefit from having more choice about how their support needs are met, including who provides their support, how their support is delivered and planned. They have more control over the whole process and have the flexibility to adapt and personalise support to their individual circumstances. The number of staff providing formal support has often been reduced which in turn leads to better and stronger relationships between the person with dementia and the smaller staff team they have supporting them, this can also help to reduced anxiety and promote more outcomes focused support.

Carers of people with dementia say that they benefit from knowing the support their loved ones are receiving is achieving positive outcomes, increasing their quality of life and reducing the risk of the caring relationship breaking down.

5.3 Cost-effectiveness

The pilot set out to demonstrate that self-directed support is a practical, cost-effective approach to providing more personalised services which allow someone with dementia who would otherwise be likely to enter a care home to stay in their own home, when that is what they and their families choose. In addition to the clear evidence of the success in improving the outcomes for the people who participated in the pilot and accessed SDS, the cost-effectiveness of the approach is clear.
<table>
<thead>
<tr>
<th>COUNCIL AREA</th>
<th>Weekly hours allocated, all packages</th>
<th>Average hourly rate in direct payment</th>
<th>Average weekly overall cost</th>
<th>No of referrals</th>
<th>No. of SDS packages</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Ayrshire</td>
<td>155</td>
<td>£11.78</td>
<td>£1,825.90</td>
<td>19</td>
<td>7</td>
</tr>
<tr>
<td>South Ayrshire</td>
<td>82.5 + Laundry Service</td>
<td>£10.67</td>
<td>£927.34</td>
<td>23</td>
<td>6</td>
</tr>
<tr>
<td>East Ayrshire</td>
<td>151.75</td>
<td>£10.62</td>
<td>£1,611.59</td>
<td>27</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>389.25 + laundry service</td>
<td></td>
<td>£4,364.83</td>
<td>69</td>
<td>21</td>
</tr>
<tr>
<td><strong>Average cost of package</strong>&lt;sup&gt;15&lt;/sup&gt;</td>
<td></td>
<td></td>
<td><strong>£207.85</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The SDS packages required for the 21 individuals included cost an average of £207.85.

It is important to note that the costs of support for people living at home or in a care home may fall on the individual and/or the public purse, depending on the person’s circumstances. The figures above take no account of each individual’s financial assessment or whether the cost of care home fees would have come from the public purse. It is also the case that care home fees include ‘hotel costs’ covering food and accommodation.

However, what these figures do show is that the SDS packages were not unrealistically expensive.

Individual circumstances and local authority charges can vary greatly and it is not possible to explore every potential situation. However, it is likely that for a single person on a state pension with the standard minimum guarantee of pension credit of £137.35 (2011/12) most or all of the cost of a support package at home would be met by the local authority, including through free personal care, and depending on financial assessment, and the individual may also use Attendance Allowance which is provided by the state.

Care home fees in Scotland in 2011 were £474.16 or £550.81 with nursing care. A single person on a state pension with the standard minimum guarantee of pension credit of £137.35 would keep a personal expenses allowance of £22.60 and contribute the remaining £114.75, with the local authority meeting the remaining £359.41 (or £436.06 with nursing care).

In this case using the average figure for an SDS package in this pilot, the saving to the public purse would be £151.56 (or £228.21 with nursing care), or a potential annualised saving of £7881.12 (£11,866.92).

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<sup>15</sup> The above information relates to 21 out of the 23 SDS packages, as we did not have enough information to include 2 outcomes.
Clearly this level of saving would not be realised for every individual, as people with more substantial resources would pay a greater proportion of care home fees and any non-personal care element of their support at home.

Due to the finite nature of the pilot, it is not possible to say how long on average participants were able to stay at home. However, the available data is in the chart below.

<table>
<thead>
<tr>
<th>Duration of period at home using SDS</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 6 months</td>
<td>3</td>
</tr>
<tr>
<td>6-12 months</td>
<td>3</td>
</tr>
<tr>
<td>Over 1 year</td>
<td>7</td>
</tr>
<tr>
<td>Under 1 year at end of pilot but continuing</td>
<td>7</td>
</tr>
<tr>
<td>Not known</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>23</strong></td>
</tr>
</tbody>
</table>

This illustrates that although the nature of dementia is progressive and some people will not be able to live at home until the end of their life, access to SDS successfully supported people to exercise their choice to stay at home for significant periods.

The pilot has proved that local authorities can benefit from using limited resources to achieve better outcomes for individuals that can significantly delay admission to care homes for many people with dementia. This has been achieved at an overall lower cost than the provision of long term care in a care home.

There is potential benefit too to health boards, from enabling people to manage their condition for longer with reduced and shorter admissions to hospital. The breakdown of relationship or physical deterioration of the carers’ health can also lead to emergency admissions to hospital. The pilot showed that families could successfully use SDS to shape support to their own circumstances, which could reduce the pressure of caring and potentially its health impact.

The pilot has proved that local authorities can benefit from using limited resources to achieve better outcomes from individuals at an overall lower cost to the provision of long term care in a care home or can delay admission to care homes for months, if not years, for many people with dementia.

There is potential benefit too to health boards, from enabling people to manage their condition for longer with reduced and shorter admissions to hospital. The breakdown of relationship or physical deterioration of the carers’ health can also lead to emergency admissions to hospital. The pilot showed that families could successfully use SDS to shape support to their own circumstances, which could reduce the pressure of caring and potentially its health impact.
6. Recommendations

The key recommendation from the Ayrshire SDS pilot is that people with dementia and their families should be actively facilitated to consider using SDS both as an alternative to care home admission for the person with dementia and at earlier stages in the journey of dementia, in order to provide the best possible outcomes through shaping their support to fit their lives and to make best use of their natural supports.

The learning from the pilot project has also led to a number of recommendations to increase and improve the use of SDS:

- Local authorities and health boards should provide further training on SDS to staff to improve understanding of SDS and of their role in supporting people through the process. Alongside this there should be a clear pathway to access SDS for staff

- Additional training and risk management procedures should be provided to budget holders to overcome concerns about people misappropriating public funds

- Staff at senior levels in local authorities and health boards should provide strong leadership within their organisations to champion SDS

- Local authorities should review their budgets and commissioning practices to ensure SDS is more accessible for people with dementia

- Local authorities should simplify paperwork and processes to access SDS, and the person with dementia or their attorney should be able to apply for SDS at any time, without the need for further assessments if they are already in receipt of services and have an up-to-date assessment

- Each local authority should make information about SDS and their local policies/procedures available in a wide range of formats, including on the internet and in leaflet form, which should be available in a range of local resources

- Independent advice services should be available much earlier in the process and would benefit from being funded on a national level to increase their independence from local authorities who they may have to challenge, which can create a conflict of interests

- Local authorities should review direct payment rates and the availability of alternative methods of using SDS such as individual service funds

- Local authorities in conjunction with COSLA, CIPFA and the Scottish Government should review their local charging policies to avoid inequity for people using SDS compared with traditional services

- Planning and commissioning of services for people with dementia should be more about achieving a good quality of life and should be person and relationship centred rather than task-based
- Discharge planning from hospital should begin from the point of admission unless the person is seriously ill and SDS application processes should be able to continue during a temporary admission to avoid unnecessary delays

- Care management staff should support families to design crisis management plans.
7. Conclusion

The Ayrshire SDS Pilot has shown that SDS can and does work just as well for people with dementia as other people with additional support needs. Historical, cultural and practice issues mean that delivering SDS to people with dementia has been slow to progress. However, this two-year pilot, with two staff, successfully worked with local authority and health partners to find ways through the barriers of awareness, culture and process and facilitated 23 people to receive SDS.

The pilot has demonstrated that the benefits of SDS, both in terms of people’s wellbeing and in terms of cost-effectiveness, outweigh the challenges people face when trying to access it. However, it remains the case that people with dementia and their families need more unbiased information about their choices and support to make informed decisions.

Current methods of financing, commissioning and planning services for people with dementia are creating a barrier to people with dementia being able to access SDS on a more equitable basis. However the outcome of this pilot is clear. SDS can be a more cost effective method and can provide better outcomes for people with dementia and their families.
8. Appendix One

Alzheimer Scotland Self-Directed Support Project Ayrshire

Terms of Reference for Project Steering Group and Operational Group

Background
The Scottish Government have funded Alzheimer Scotland to deliver a two-year pilot demonstrating best practice in supporting people with moderate to severe dementia facing the prospect of long stay care, and their families, to design creative, personalised solutions using SDS, as an alternative to institutionalised care.

We aim to demonstrate that SDS is a practical, cost-effective approach to providing more personalised services which better support both the person with dementia and the carer and family and which allow the person to stay in their own home, when that is what they and their families choose.

The pilot project
The pilot project will cover East, North and South Ayrshire, which combined have approximately 4,500 – 5,000 people with dementia, a large enough population to allow sufficient referrals. The three authorities have a mixture of urban and rural areas.

Alzheimer Scotland benefits from having well-established services in all three authorities. Our existing relationships with the local authorities and with other service providers place us in a strong position to work with local partners to identify people who might benefit from the pilot, to invite referrals, and to facilitate the development of flexible support arrangements.

The project is managed by Alzheimer Scotland, working with the three Councils in Ayrshire, and Ayrshire & Arran Health Board. It will be guided strategically by a Steering Group and will be assisted by an operational group. This paper describes the remits and membership of the two groups.

Project aims
The pilot project will aim to:

- Work directly with individual people with dementia and their carers and families to assist them to explore options for the care of the person with dementia, maximising natural supports and using purchased services or employing personal assistants

- Assist families to consider the full range of funding options including direct payments, or individualised budgets where these can be negotiated, and to set up mechanisms for managing any payments on behalf of the person with dementia, and link them into organisations supporting employers of personal assistants where appropriate

- Work with social work staff to assist them to develop their practice in order to offer SDS to more people with dementia
- Work with organisations supporting the employment of personal assistants to ensure that they are dementia-friendly and to ensure that personal assistants can access dementia training
- Work with the Alzheimer Scotland Dementia Helpline to raise awareness of self-directed support and to provide information
- Collect success stories and disseminate these through the Alzheimer Scotland website and through contributions to publications and conferences and publish a report of the pilot.

**Project Steering Group**

**Membership**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kate Fearnley</td>
<td>Director of Personalisation, Alzheimer Scotland</td>
</tr>
<tr>
<td>Jane Duffy</td>
<td>Community Care Manager, East Ayrshire Council</td>
</tr>
<tr>
<td>Alan Brown</td>
<td>Operational Manager, North Ayrshire Council</td>
</tr>
<tr>
<td>Liz Vance</td>
<td>Assistant Community Care Manager Older People, South Ayrshire Council</td>
</tr>
<tr>
<td>Julie Barron</td>
<td>Regional Manager, Ayrshire and Dumfries &amp; Galloway, Alzheimer Scotland</td>
</tr>
<tr>
<td>Isabel Marr</td>
<td>Services Manager Elderly Services, NHS Ayrshire &amp; Arran</td>
</tr>
<tr>
<td>Yvonne Stewart</td>
<td>Project Manager, Alzheimer Scotland, Self-Directed Support Project</td>
</tr>
</tbody>
</table>

**Remit**

The Project Manager will report on a three monthly basis to the Project Steering Group. The Group will:

- Provide strategic direction and leadership for the project
- Provide accountability for the project
- Provide accountability for use of project funds
- Oversee the development of a framework for delivery of the project
- Monitor performance
- Provide advice and support to the Practice Manager
- Oversee the evaluation of the project, including consideration of options for the future
- Enable appropriate networking opportunities
- Consider an exit or continuation strategy.
Operational Group
Membership

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Julie Barron</td>
<td>Regional Manager, Alzheimer Scotland</td>
</tr>
<tr>
<td>Claire Mills</td>
<td>Team Manager Independent Living, East Ayrshire Council</td>
</tr>
<tr>
<td>Joanne Hughes</td>
<td>Team Manager, Older People’s Service, East Ayrshire Council</td>
</tr>
<tr>
<td>Mary McLelland</td>
<td>Representative North Ayrshire Council</td>
</tr>
<tr>
<td>Jackie Powell</td>
<td>Representative South Ayrshire Council</td>
</tr>
<tr>
<td>Yvonne Stewart</td>
<td>Project Manager, Alzheimer Scotland</td>
</tr>
<tr>
<td>Evelyn Gilchrist</td>
<td>Representative from Ayrshire Independent Living Network</td>
</tr>
<tr>
<td>Susan Maxwell</td>
<td>Service Manager, Alzheimer Scotland, North Ayrshire</td>
</tr>
<tr>
<td>Moira Robinson</td>
<td>Service Manager, Alzheimer Scotland, East Ayrshire</td>
</tr>
<tr>
<td>Helen Wilson</td>
<td>Carer</td>
</tr>
<tr>
<td>Linda Mason</td>
<td>SADSA</td>
</tr>
</tbody>
</table>

Remit

The Project Manager will co-ordinate/facilitate these meetings on a regular basis and no less than bi-monthly.

The group will:

- Offer support and advice
- Provide assistance in planning project delivery/work plan
- Assist with overcoming obstacles
- Signpost staff to local networks
- Assist in promoting the work of the project and cascading information
- Assist in ensuring appropriate referral systems
- Contribute to monitoring and evaluation of project.

May 2009
Response to Scottish Government’s Self-directed support:
A National Strategy for Scotland consultation

7 May 2010
Contents

INTRODUCTION  53
  Dementia  53
  Self-directed support and dementia  53
  Self-Directed Support Strategy consultation  54

KEY COMMENTS  54
  Move to self-directed support as default position  55
  Managing a direct payment  55
  Better information and improved professional awareness  55
  Eligibility criteria and lack of early intervention  47
  Beyond direct payments- other forms of self-directed support  56
  Hourly rates and outcomes  56
  Providers and the social care market  57
  Brokerage  57
  Employing PAs  57

RESULTS FROM THE CONSULTATION EVENT  58
  Making self-directed support work for people with dementia  58
    Communication & information  58
    Assessment and eligibility  59
    Budgets  60
    Process  61
    Support  62
  What does self-directed support mean at the early stages of dementia?  63
  What does self-directed support mean at the middle stages of dementia?  63
  What does self-directed support mean at the advanced stages of dementia?  64

CONCLUSION  65

APPENDIX 1 - SCRIBE NOTES FROM KILMARNOCK EVENT  67
APPENDIX 2 - QUESTIONNAIRE RESPONSES  68
APPENDIX 3 EVALUATION FORM RESPONSES  69
Introduction

Alzheimer Scotland is Scotland’s leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people with dementia and carers in getting their views and experiences heard. We provide specialist services such as day care, home support and carer support (through training programmes and support groups) in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications. We welcome the opportunity to comment on the Self-directed support strategy for Scotland.

Alzheimer Scotland was funded by the Scottish Government to carry out a consultation event in March with people with dementia and their carers on the draft national strategy for SDS in Scotland. This response is informed by the outcome of that day, and the quotes in italics are from the carers and people with dementia who attended.

The response is additionally informed by the Alzheimer Scotland pilot projects and the experience of the individuals they have supported to access SDS, and by Alzheimer Scotland’s research report, Let’s get personal – personalisation and dementia. Our response is in three parts; an introduction, a set of key comments on the strategy document, and feedback from the consultation event.

Dementia

Dementia is a global term used to describe a range of brain diseases characterised by a progressive decline in intellectual and other mental functions. Whilst Alzheimer’s disease and vascular disease represent the most common causes, there are a number of other less common forms of dementia.

There are currently 71,000 people with dementia in Scotland, around 2,300 of whom are under the age of 65. It is the second highest contributor to years lived with a disability for people over 60\(^{16}\). As our population ages the number of people with dementia is set to double over the next 25 years.

Self-directed support and dementia

Currently very few people with dementia use SDS throughout Scotland. It is estimated that only around 300 people with dementia in Scotland use a Direct Payment\(^{17}\).

In 2009 the Scottish Government funded Alzheimer Scotland to host a pilot project which offers support and assistance to people with dementia and their families to find alternatives to entering a care home using SDS. In addition, our second Scottish Government-funded pilot on post diagnostic support has a key focus on enabling people to plan for and take control of their future support needs. Experience from these projects has been helpful in identifying the barriers people with dementia may encounter when trying to access SDS at different stages of dementia.

\(^{17}\) Alzheimer Scotland (2010) Let’s get personal – personalisation and dementia. Edinburgh
Five local authorities and two health boards are involved in the pilots and are working in partnership with Alzheimer Scotland to overcome the barriers and make SDS more accessible for people with dementia and their families.

**Self-Directed Support Strategy consultation**

The consultation event took place on 30 March 2010 at The Park Hotel in Kilmarnock. Despite severe weather conditions over 70 people attended; most were people with dementia and members of their families. The original target was 30-40 people either using or thinking about using SDS.

Publicity event was focused on the two geographical locations covered by the pilot projects (Ayrshire and Arran, East Renfrewshire and Renfrewshire), and neighbouring Inverclyde, West Dunbartonshire and Helensburgh areas and was distributed through Alzheimer Scotland and via social work, health, voluntary organisations and local media.

To enable as many people as possible to attend we offered re-imbursement of travel costs, help with travel arrangements, carer support and individual support for people with dementia. The format of the consultation event consisted of an introductory presentation by Henry Simmons, Chief Executive, Alzheimer Scotland who set the scene for the day. Lindsay Kinnaird, Policy & Research Officer, Alzheimer Scotland presented on findings from research conducted with people with dementia using direct payments and John Smillie, a participant from Alzheimer Scotland’s Ayrshire pilot project talked about how he uses the Direct Payment to provide care for his mother who has dementia and has remained living in her own home as an alternative to long term residential care.

The presentations were followed by a very interactive and lively question and answer session. Two group discussion sessions in 6 groups, facilitated by direct payment managers from 4 different local authorities and Alzheimer Scotland staff and supported by scribes.

The first session was “What would make self-directed support work for people with dementia?” and the 2nd session on “What does self-directed support mean at different stages of the illness?”; for this session, participants chose to discuss either, early, mid or advanced stages of dementia.

At the end of the event a feedback session was hosted by Kate Fearnley, Director of Personalisation, Alzheimer Scotland.

The responses to a participant questionnaire and the evaluation form are in Appendix 2. We would like to thank everyone who braved the severe weather conditions to come along and give their views.

“The event made me feel as if my views are important…. the feeling of being part of a group of like minded people makes me feel quite emotional. I feel that since becoming involved with Alzheimer Scotland my mood has lifted, and I have a purpose again in life….due to events like Kilmarnock” (Person with dementia)

**Key comments**

Alzheimer Scotland welcomes the values and principles set out as underpinning the SDS strategy. We see the personalisation of social care services as essential if Scotland is to make
best use of scarce resources in an era of increasing demand. We recognise that it is a vision which cannot be delivered immediately, but we hope that our comments below will help to make the final strategy as effective as possible in transforming the organisation of social care and engendering the cultural changes that must happen if this is to succeed.

The points below are the key areas where we believe that the strategy could be strengthened.

**Move to self-directed support as default position**

Alzheimer Scotland agrees strongly SDS must be made available to everyone. Both Alzheimer Scotland’s research and our pilot projects have shown conclusively that, when empowered to direct their own support, families effectively combine state resources around their own natural supports – creating a truly personalised care package. However the current system, limited as it is to direct payments which are often not offered, is failing people with dementia. We believe that as a result of factors including ageism, assumptions about dementia and the entrenched patterns of support they are currently generally restricted to, people with dementia and their families could well continue to be denied the opportunity to benefit from choice and control unless personalisation becomes the system not an add-on or peripheral option. **The strategy should explicitly state that SDS should become the default option offered.** We do agree however, that there should be an opt-out for those who do not wish to arrange their own support, as is likely to be the case for some people with dementia and their families.

**Managing a direct payment**

We would like the strategy to **recommend broadening out the ability to consent to and manage a direct payment to include an appropriate person such as a carer, as in England**, as the current requirement to have a power of attorney or guardianship is unduly restrictive for people with dementia and their families. The use of the Access to Funds provision within the Adults with Incapacity Act should be considered, in order to provide a safeguard.

**Better information and improved professional awareness**

The lack of information, accurate and unbiased, about SDS was a recurring theme of the consultation event and of our research. Our study showed that the way direct payments are presented to potential recipients can be shaped by professionals’ own views.

> “I’ve tried to ask about direct payments but it’s blocked – they [social work] completely talked me out of it”  (Carer)

Better signposting and increased general awareness of SDS within health, social work and voluntary sector is essential. We see Recommendation 2 as starting to address this but given that newly-trained professionals will enter existing organisational cultures, we do not see it as adequate on its own as providing effective leadership in the short to medium term. We would like to see a **recommendation about requirements for training of the existing workforce.** There is also no mention in the strategy about promoting SDS to groups of people (such as people with dementia) who are not traditionally seen as potential recipients in order to improve the uptake.

> “It’s been 10 years [of caring for husband with dementia] and I’m just finding out about this [SDS] now.” (Carer)
Eligibility criteria and lack of early intervention
The gap in early, preventive, support for people with dementia, and the impact this lack has in increasing the need for expensive interventions such as long term care are now recognised, and Alzheimer Scotland’s Renfrewshire/East Renfrewshire Post-Diagnostic Pilot is seeking to demonstrate how this can be addressed. We welcome Recommendation 1 that the impact of eligibility criteria be reviewed but believe that access to low-level, preventative individual budgets which help people with conditions such as dementia retain their independence and natural supports should form a separate recommendation.

Beyond direct payments - other forms of self-directed support
As our research, Let’s get personal, has shown and the consultation event and pilot projects are also highlighting, there are many limitations of direct payments as a mechanism. We support the wider definition of SDS in the draft strategy, and would like to see Recommendation 8 strengthened to include the intention that within a defined timescale all local authorities should individualise budgets so that they are able to offer the full range of options to people using SDS.

We would like Recommendation 9 to include the expectation that any resource allocation system adopted should be based on co-production, reflecting the values stated in the draft strategy. Currently people with dementia and their carers report feeling uninvolved in assessment and feel little choice or control over what services are offered or received.

“A shared assessment was done, but it wasn’t shared with us.” (Carer)

We would also like to see the explicit statement that resource allocation systems should be equitable across age and care groups. There are proportionately fewer resources in social care funding for older people compared to other groups\(^\text{18}\); there is also a propensity towards personal care, as opposed to social support, and an expectation that older people lead more restricted lives than younger adults\(^\text{19}\).

“It’s about support that keeps people doing what they’ve always done, not just the basic of staying alive – and keeps carers having a life too.” (Carer)

Hourly rates and outcomes
There are many problems with the way that direct payment hourly rates currently operate. Our own research\(^\text{20}\) found that there is wide variation between local authorities operating a range of rates, with the lower rate ranging from £6.58 to £12.07 and the higher rates from £11.42 to £22.50. There was also some variation between authorities with a single flat rate, ranging from £10.20 to £11.42.

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19 Alzheimer Scotland (2010) op cit
20 Alzheimer Scotland (2010) op cit
There is no consistency in the factors used to determine the hourly rate paid, which included client group, type of support and whether a PA or an agency was used. Similarly there was a range of approaches to whether authorities would allow recipients to purchase support from an agency with a higher hourly rate than their set rates, some might pay a higher rate, some would allow the person to purchase fewer hours and some would allow the person to top-up the direct payment level\(^21\).

These variations are clearly unfair. However, the more fundamental problem, as recognised in the strategy, is that the conceptualisation of the support that people require into hours of support is unhelpful and restrictive.

Although we agree that the analysis in Recommendation 13 would be useful, we also believe that **a much stronger statement should be made that the allocation of an individual budget, whether or not it is paid via a direct payment, should not be restricted to the provision of hours of support on a like-for-like basis, and that the rates paid to achieve agreed outcomes should be agreed on an individual basis rather than artificially and inequitably capped.** It is also the case that carers’ lives are also very much impacted upon. Carer-defined outcomes are very important to making SDS work for people with dementia and must be taken into account.

**Providers and the social care market**

As a provider organisation, we strongly agree with this section and the link made to the forthcoming social care procurement guidance. We would like to see **Recommendation 18 made stronger to emphasise intended shift towards individual commissioning.**

**Brokerage**

There is only one mention of brokerage in the strategy, and we feel this is an area needing further attention. Our pilot project has been providing brokerage, and the voluntary sector may be well-placed to offer brokerage, but will need to be resourced to develop and maintain the necessary knowledge and expertise and to provide the service. It is also the case that the role of care managers should shift towards including brokerage.

**Employing PAs**

We agree with the section on employing personal assistants, but would like a **more explicit statement that both PA employers and PAs must not be financially disadvantaged and that the full cost of recruiting, employing, training and maintaining staff including accessing appropriate support services should be covered.**

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\(^21\) These were not mutually exclusive policies with some local authorities taking more than one approach when the recipient wished to purchase support from a more expensive provider.
Results from the consultation event

This section reports the results of the consultation event for people with dementia and carers hosted by Alzheimer Scotland in March 2010 in Kilmarnock. Participants identified the barriers they had faced to accessing and using SDS (usually direct payments) and the solutions they would like to see. They also looked at what self-directed support can mean at each stage of dementia.

Making self-directed support work for people with dementia

Communication & information

Barriers - Many people felt self-directed support is somewhat of a ‘myth’ and is surrounded by a lot of ‘negativity’.

“I look after my Dad and nothing like this (SDS) has ever been mentioned” (Carer)

Professional attitudes about SDS can be negative and put people off applying for it.

“The first I heard of it [SDS] wasn’t from social work but from Alzheimer Scotland”

Care managers in older people’s teams/community mental health teams (those most likely to be supporting people with dementia) were felt to have low levels of awareness and understanding of SDS.

“The CPN mentioned it [SDS] but that was it – I just know of it, not about it”

“It shouldn’t be a postcode lottery or depend on who you speak to. You should be able to go to any professional involved in care and they could tell you [about SDS] – there’s no room for anomalies in health care”

Participants felt that there is too much use of jargon to explain and inform about SDS and information is not freely available.

Lack of awareness in the general public about dementia can delay a person receiving a diagnosis and asking for help. There is often a stigma attached to asking for help/support and people often don’t know what you are entitled to and how to get it. Many years after diagnosis of dementia people with the condition and their carers still unaware of the existence of SDS or have very limited knowledge about it. This denies people with dementia the opportunity to plan in advance.

“It’s been 10 years [of caring for husband with dementia] and I’m just finding out about this [SDS] now.”

It is difficult for individuals to find positive stories of people who have dementia using SDS.
Solutions – Information needs to be given using plain language which is simple, independent and non-biased. Ensure provision of concise, consistent information, including information about the person with dementia’s rights, assessment process, local eligibility criteria and SDS.

“Provide information packs for people with dementia and their carers”

Provide positive examples of how people with dementia are using SDS.

“Include people with dementia in the publicity and promotional materials”

Information should be provided at earliest opportunity and professionals should take a proactive approach.

Information about support organisations should be made readily available: people wanted a person available to explain and guide them through the process, answering any questions, and possibly connecting to other people using SDS, perhaps through the use of a ‘buddy system’.

To increase levels of professional knowledge and understanding SDS, training needs to be more comprehensive and include the range of professionals that person with dementia comes into contact with such as GPs, consultants, allied health professionals, and social work staff. This should form part of integrated care pathways for people with dementia.

Information should also be easily accessible within the community and much more widely publicised (e.g. community centres, carers’ centres, post offices etc).

Participants felt that there should be a national media campaign.

Assessment and eligibility

Barriers - Eligibility criteria can often make it difficult for people to receive support at the earlier stages of dementia, and this lack of early support and intervention, current assessment process was felt to be unfair and puts many people with dementia at a disadvantage. Carers’ needs are not always recognised and considered when planning care.

“They’re [professionals] trying to fit people’s lives into the system”

There is too much paper work and duplication of paperwork. Social work and health systems are not always compatible and leads to people having to go through multiple assessments. Assessments are based on need and not outcomes the individual with dementia wishes to achieve.

“It’s about support that keeps people doing what they’ve always done, not just the basic of staying alive – and keeps carers having a life too.”

Some people felt excluded from the assessment process and did not know that the assessment document should be shared with them when complete.

“A shared assessment was done, but it wasn’t shared with us.”
Self-assessment and co-production does not exist, the person with dementia and their families felt they had little choice or control over what services were offered or received.

**Solutions** – People need to be given information at the right time for them and not wait until point of crisis when applying for SDS can be an added stress that carers are unable to consider.

SDS assessment should become usual practice and be triggered automatically, rather than opting in.

“People and systems must adapt”

Eligibility needs to be from onset of dementia where there is role for preventative support and/or advanced planning. Managing a small budget at earlier stage may enable people to become more familiarised with processes and more able to manage larger and more complex packages later on, therefore giving people the choice to stay at home and remain connected to friends, family and community.

Carers involved as appropriate at all stages of SDS process.

“The hospital knew her diagnosis but I didn’t, but I was dealing with the behaviour – you’re stuck in the middle”

One assessment, which is user led, should be carried out and information shared appropriately, ensuring that the person with dementia has the right to a family member/representative being present at assessment.

**Carers “stuck in the middle”**

There should be better and wider use of carers’ assessment. Assessments should be carried out by person with awareness of dementia and ensure the person with dementia receives a copy of the assessment.

The assessment process needs to change to be more outcomes-focused rather than needs/service led such as the single shared assessment. Tools such as ‘Talking Points’ should be more widely used to ensure the person with dementia and their families are achieving the outcomes that are important to them and not offered services that fail to achieve their desired result.

“Once information is given to officialdom they control it, then somebody decides what services should be given but not with us”

Assessors need to have the right information to ensure people can make informed choices about SDS; wider use of independent support organisation will enable people to receive unbiased information on the realities of SDS.

**Budgets**

**Barriers** - There is a lack of flexibility in local authority and health budgets, limited resources and few appropriate services for people under 65. Different levels of direct payment rates
cause inequality and make consistency difficult and limited budget (if any) for direct payments within local authorities. Waiting lists, overspent budgets, budgets allocated to block contracted/building based services can mean despite the person meeting eligibility criteria to access SDS it can be difficult to actually do so.

“More funding available for care within the home!”

Different budgets are managed and controlled by different departments and ring-fenced for particular services/clients and this can make it difficult to access direct payments for all assessed needs. For example people may only be able to access real choice and control over one element of the care needs such as personal care as other services such as day care and respite care may not be available via a direct payment.

We have an ageing population and demand for services is increasing while funding is decreasing.

The rates applied to direct payments can be significantly less than that of in-house or contract services provided to local authorities. This limits the choice of providers that direct payment recipients can choose from and creates an inequality with those who choose the traditional routes to services.

There is inequality between what is free from traditional services and what a direct payment recipient may receive. For example in some local authorities, transport to day care is free but a person who chooses to take a direct payment instead of traditional day care may not receive any transport costs within their direct payment and therefore is clearly disadvantaged.

**Solutions** - Free up resources including health, social work and housing, to allow for more creative use of budgets. Ensure people accessing SDS are able to access equitable resources that they would have received if they had chosen to use traditional model of service delivery and recognise that traditional models of service delivery might not always best meet the needs of the person with dementia and their families, and may also be more resource intensive than is required.

Ensure people with dementia and their families can exert real choice, control and flexibility over how their care and support needs are met.

Voluntary organisations can campaign/lobby government to release resources.

**Process**

**Barriers** - The process of getting a direct payment was described as being full of red tape and further complicated by the fear factors, which included financial monitoring and employing staff. One issue was whether it was possible to employ relatives; there is no definition in current guidance of what might constitute ‘exceptional circumstances’ in which this might be possible.

People felt there is little flexibility, complicated systems, responsibility & requirements and lack of balance. Carers wanted to ‘still have time to be daughter/son/wife husband’ and expressed concern about additional stress of managing a direct payment. Individuals
expressed their view that they had ‘been blocked’ by their local authority from accessing SDS.

“I’ve tried to ask about direct payments but it’s blocked – they [Social Work] completely talked me out of it”

“How come MPs can employ their relatives no questions asked but people with dementia can’t?”

It takes too long to process an application for SDS.

Solutions - Simplify the process including financial monitoring. Provide support for people to keep appropriate financial records from the beginning and not wait until a problem arises. Provide alternatives to directly employing staff and have more support available for people who do wish to employ staff.

Ensure ‘personal budgets’ available in all local authority areas and ability to use provider of choice and not just those that local authorities already contract with.

Explore different options such as third parties holding direct payments on behalf of the individual who are able and willing to deal with the stress.

Define exceptional circumstances and enable employment of relatives when appropriate checks have been completed.

Factor in ‘time-out’ for carers during assessment process to ensure they are not overloaded with caring and managing the direct payment.

Incorporate a national system that is transparent and details how many people request SDS and how many of those actually go on to receive it and record the reasons why people are not proceeding with their application for SDS. Use this information to reduce the barriers and enable more people to access the resource.

Ensure access to money quickly as debt causes further stress – set timescales.

Support

Barriers - Lack of support available to find the right support and access specialist services, little opportunity to access peer support and difficulty having the time to find out about/investigate SDS whilst caring.

[Speaking of lack of choice of types of support in existing system] “They [social work staff] have got their routines and stick with them”

Solutions – Offer a range of support services such as ‘brokers’ who can support people to find the right support for their individual needs. Ensure there is more comprehensive support with HR and payroll, opportunities for peer support with others new to SDS and sharing experiences and ways of overcoming any difficulties and ensure funding for this is incorporated into the SDS budget.
Improve the development of marketplace and enable further development of creative, flexible, specialist support services that are able to respond to the individuals needs. Ensure practical assistance with paperwork is available in all local authority areas.

**What does self-directed support mean at the early stages of dementia?**

People want earlier intervention, with move away from crisis management. Often at the earlier stages of the dementia people are not eligible for services as they are not deemed to have ‘critical or substantial’ needs, but loss of employment, difficulty maintaining social contacts and withdrawal from normal activities can lead to people with dementia becoming isolated, withdrawn and can negatively affect relationships with family and friends.

Early support and intervention enables the person with dementia and family to build up relationships with support staff, which in turn means that the person with dementia is much more able to articulate their wants, needs and how they would like to be supported. This could also help overcome reluctance to accept support that many people with dementia experience.

GPs are first point of contact and can be a gateway to information; they need to have to skills to signpost people to the right support, such as providing information on Alzheimer Scotland’s Dementia Helpline.

Information needs to be given in a sensitive manner, recognising that the time following diagnosis is a difficult time for people with dementia and their families. SDS services need to be able to offer home visits, as the person may feel there is stigma and be reluctant to seek or accept help or information and to access services. People may need support to be able to rebuild their confidence so that they can articulate what they want and recognise what support they would like in the future. There needs to be a sensitive approach to helping people think about and plan for future care needs, including if they would like to use SDS.

Use of a small budget at an early stage enables a person with dementia to access a range of post-diagnostic and community supports that might help them to come to terms with the diagnosis and to access appropriate individualised support including being able to buy small pieces of equipment that can help to maintain independence for longer.

Help and guidance to put in place power of attorney and advanced statements will help ensure the person remains at centre of care in the future and that their wishes are clearly stated and can be understood when they are unable to express their wishes or lack the capacity to do so. A small amount of information and support at early stage enables person to access more information and support as the illness progresses.

“More control of care EMPOWERS”

**What does self-directed support mean at the middle stages of dementia?**

It is important to have received the right support at the early stage of dementia; this empowers the person with dementia to make informed choices about how they would like to be supported at the point that they become eligible for formal support services.
“A lot of direct payments are done in crisis, but they shouldn’t be, it should be pre-planned. I want to help people think out of the box, but you can’t do that if it’s a crisis.” (Professional)

Anecdotal evidence suggests the process of receiving a diagnosis may have taken longer for people under 65 years so that they may be coming into contact with services at a more advanced stage of the illness. For people under 65 years there is a lack of age appropriate services and SDS may be more appropriate to develop more personalised support.

It is important to be able to access flexible services that can respond to a person’s individual needs and circumstances, keeping them connected to their community and natural supports. Carers’ needs must be considered to ensure they do not withdraw from their natural support networks, regular time out from caring responsibilities may enable the carer to continue caring for longer.

Carers often ‘take up the slack’ and provide a lot of hidden care such as dealing with finances, paying bills, maintaining the household (gardening, cleaning, shopping, re-decorating, laundry etc), support to attend appointments (medical, dental, assessment etc) and social support/stimulation. Carers need support to ensure that they have a life too.

The person with dementia can become overly reliant on informal family carers and be reluctant to accept support from formal carers/services.

What does self-directed support mean at the advanced stages of dementia?
For many people the illness can deteriorate rapidly at the advanced stages. It is important to have had the support to plan and make informed choices and decisions. Often admission to hospital or emergency respite will result in admission to care home, even when this is against the person with dementia and their families’ wishes.

“Hospital to nursing homes (not always appropriate)”

There is a need for more options to be available, including specialist palliative care services, which can be purchased using SDS. The assessment process needs to be flexible enough to respond to changing needs. It is paramount that carers get the right support at this stage as it can be such an intensive, stressful time which can lead to the carer having health problems and possibly being unable to continue to provide ongoing support. For people under 65 years, traditional models of residential care can be particularly inappropriate to meet their needs. Carers need to remain connected to their friends, families and community and not feel guilty that they are failing in their responsibilities to the person with dementia.

“I wouldn’t want to be paid for the care I give my mother – I’d want to use a payment to get help from someone else, not take it all on myself”

Carers may be happy to continue to provide support with tasks normally offered via formal services such as personal care but need other, more flexible support which may incur a charge.

“Family will make it work, if no family much harder”
Conclusion

It is essential that the Self-directed Support Strategy, in conjunction with the National Dementia Strategy, provides a clear message on the direction of travel towards greater personalisation of health and social care so that the majority of people with dementia and their carers have genuine choice and control.

Alzheimer Scotland believes that transformational change is necessary. We are in agreement with the thrust of the draft strategy, and hope that the comments we have made based on the feedback of people with dementia and their families and on our own research, will be helpful in strengthening the strategy in order to achieve the fundamental changes that are needed if the social care system is to become fit for the future.
Appendix 1 - Scribe Notes from Kilmarnock Event

What would make self directed support work?
- More information (dementia and SDS)
- A Buddy (an. other) to help & support
- Need more connections GP/CPN/SW
- Freedom of information
- Social work has lack of understanding of SDS
- Needs to be positive
- Too bureaucratic
- It’s a myth
- Inform GPs of SDS
- EAC “blocked” Alzheimer Scotland for a care package
- Anomalies – Post Code Lottery
- Professionals SHOULD know
- Lack of neurologist in EAC
- Carers “stuck in the middle”
- Crisis management/need information
- Having NHS Funding available as part of the package
- Someone taking responsibility post-diagnosis – GPs & Consultants should give information post-diagnosis
- Clearly define what “exceptional circumstances” are and enable greater flexibility (MPs can employ close family members – why not SDS recipients)
- People and systems must adapt.

Publicity & promotion
- Information prior to diagnosis
- Inform health professionals about SDS, GPs, Psychiatrists
- Family members to be supported & directed to where to get help
- Readily accessible information for family
- Carers Centres/Community Centres – widely publicise
- Publicise Self-Referral as option
- Simple Straight forward information
- Information available from diagnosis
- Pro-active – someone to talk us through SDS as an option at early stage
- SDS as default position
- Promote more generally
- Discuss right from the point of diagnosis
- Provide information packs for people with dementia and their carers
- Promote through Social Work, Government and Local Agencies
- Use variety of media including TV, Radio, Literature
- Include people with dementia in the publicity and promotional materials
- At assessment provide check list for offering SDS and the benefits
- Help to recruit private carers might be there through employment agencies
- Keep it simple – key information
- Age concern network across Scotland seems good can we learn from their model? – Don’t re-invent the wheel
• Link in with carer agencies

How?
• Leaflets
• Information packs
• Involve family more
• Pack with info of other supportive organisations
• Co-ordinator within GP Practice to direct people for support
• Put literature in surgeries
• Automatic trigger point
• Support the individual to make the decisions about their needs.

Support through process of assessment
• One assessment carried out and information shared appropriately
• Assessment to be user led not service led
• Family/representative present when assessment is being done
• Getting the balance right for the individual being assessed and carers
• More use of carers assessments
• Care agency informed of details in the assessment to be informed of person being cared for
• People to have the opportunity to read assessment & challenge the information that may not be correct.
• Dementia training to people carrying out assessments
• Who should carry out assessment?

What are the barriers?
• Communication
• What can we do? How can we use it?
• Experts professional view can override carers view
• Carers not recognised as experts
• Assessor not knowledgeable about SDS or dementia
• People not recognising needs
• Information
• Some positives but if’s finding them
• Positive aspects/superb clinic
• Myths about SDS
• Lack of awareness
• Where information comes from
• Finding the right support
• Fair & accurate assessments
• Not having early intervention impacts on the person being cared for & the carer
• Fear factor
• Eligibility criteria
• Jargon & negativity of information
• Lack of awareness of SDS
• Eligibility criteria
• Finding the right support
• Negativity & myths about SDS
- Fear factor
- Lack of early intervention impacts on the carer & the person being cared for
- Not having a fair and accurate assessment
- Jargon
- Employing staff – red tape
- Financial monitoring
- Lack of peer support
- Length of time the process can take
- Simplify the process
- Balance needed – still have time to be daughter/son/wife/husband
- Someone needed to help set up support required
- Don’t want stress of managing direct payment
- Limited budgets within local authorities
- Having the time to find out/investigate whilst caring
- General lack of awareness in public about dementia can delay person receiving diagnosis/asking for help
- Years after diagnosis people still unaware of SDS
- No information about SDS
- Not being offered a Direct Payment
- Lack of clarity of information/guidance
- Inconsistencies across areas
- Issues arising from consent and power of attorney
- Some benefits not available to under 65’s
- Waiting lists
- Misinformation
- Postcode lottery
- Social workers don’t know enough about it
- Co-production doesn’t exist
- Services decided for you not with you
- No shared care approach between services
- Lack of transparency (personal budgets – resource allocation)
- Too service led – needs to be personalised
- Five years from diagnosis and still no knowledge of SDS
- No-one with dementia in the publicity materials
- Age discrimination
- No choice given – day care only option offered but not right for everyone causing frustration and upset for whole families
- Loss of privacy and control
- Within day care experienced no choice of activities
- Assessments not shared with person with dementia and families
- System to slow from need to payment – need to get in early to be successful
- MMHS form is poor indication to determine when support needed score and abilities don’t always match
- People don’t know what they are entitled to and therefore don’t take it up
- Sometimes person with dementia says no help needed and people withdraw
- Information is currently not getting through at present
Having someone like Yvonne is great [SDS Pilot Project] but not everyone has one — who else can help?
Use sources of good publicity – TV, football stadiums, information boards
Social workers should be telling people.

Overcoming the barriers
- Employing staff
- Help to be creative
- Hearing about other peoples ideas
- Three levels – Strategic – Someone to do help – someone to help round the system
- Very detailed person care plans of what works for individual BUT who do you give it to – who does it like you?!
- Individual champions and seeing positive examples
- Plain language
- Peer Support for people new to SDS
- Maintaining Continuity with Staff
- Payroll – HR Issues eg employment law
- Voluntary Organisations can campaign/lobby Government to unlock resources
- Often limited to budget existing – free up resources
- Importance of timing – right time is not when in crisis
- Give examples of how it can be used
- Essential that information provided at earliest opportunity
- Direct payment – doesn’t require capacity – someone else can act on behalf of person with dementia
- Should be triggered automatically if health/SW become involved as part of assessment
- Statutory duty to offer SDS being carried out everywhere
- More early intervention
- Change eligibility criteria
- Improve joint working approach by health and social work
- Information about how it might affect Pension Credits/benefits of people recruited i.e. friends
- Letting people know how much they will receive
- Reduce complications – simplify the process
- Provide more information (too many questions – not enough answers)
- Information starts with the person with dementia, their families, friends and then the wider society

Future development/our priorities
- Knowing who can support you through the process
- Less red tape
- Opt out policy to be addressed
- Make SDS more positive and Transparent for everyone
- More personalised services
- Need flexibility in how we budget to best meet outcomes – times/types/who provides support
- Eligibility from onset of dementia if there are needs – preventative support
- Information available from diagnosis with person to help explain/guide through process/answer question
• Simplify the process and information
• Easy monitoring system
• Free up resources from Health and SW
• Need more consistency
• More Information and publicity
• More support available through the process
• Information must include structure and mechanics of accessing SDS
• Provide information and support at diagnosis
• CHOICE
• Raise awareness that SDS is a possible option
• Tell people what they are eligible to receive
• More knowledge about power of attorney
• Clarity of how eligibility is decided
• Make sure we don’t create a new monster by “individual care” agencies growing.

What can we do?
• Communication – talk talk – inform
• Inequalities – cancer v dementia
• Different levels of support from Social Workers
• Carers need to raise voices
• Carers need education
• Professional – SSA 4 Not needed- Barrier
• Ensure Time off for main carers
• Making sure voice of person with dementia/carer heard by health/SW professionals
• Opportunities to meet others in same position – support groups
• Pro-active approach to provide information on role of professionals/services
• Make sure information put in Carers Support Centres
• Peer support
• Provide specialised agencies and teams
• Provide support to prepare for assessment etc.

What does SDS mean at the early stages of dementia – planned approach
• Early intervention preventing crisis situations
• Early intervention encourages relationship build up with support staff etc…
• Lack of services for people under 65 yrs
• Services should be available to anyone regardless of age
• GPs not having information to pass on
• Information to be simplistic
• To have specialist within access from GP
• Home visits
• Sensitivity with information
• Fairness in having access to information
• Importance of early diagnosis
• Leaflet on Alzheimer Scotland Helpline
• Loss of confidence for person with dementia and so may not say what/how support should be provided
• Important to listen to person with dementia/family
• importance of choice and flexibility, time for person with dementia to build trust/familiarity/confidence
• help with recognising what support you would like in the future
• Not everyone will need formal support
• Support and information on SDS and discussions before eligibility criteria met (planning for the future)
• Regular reviews as needs change
• Face to face support available straight after diagnosis
• Panic attacks caused by fear – lack of information
• Give me information about SDS following diagnosis
• It is hard to know what you want at this point
• Need information about dementia
• We should never be left with nothing
• Time for the person to come to terms – needs more than 1 visit – longer term involvement
• Persons perceptions of difficulties may be very different from carers “I’m fine”
• Information very, very important.

What does SDS mean at the mid-stage of dementia?
• Provide social support at the right time for the person (more personal control)
• Accessing PAs & befrienders
• Clubs
• Providing support to do what they always enjoyed doing
• More awareness and information on what is available in communities
• Community resources Centres
• Better sign-posting
• Diverse Range of Community support on offer
• Carers Centres
• Both dementia specific and generic resources
• Ability to maintain everyday experiences, shopping, clubs etc….
• Access to assistive technology
• Access to small changes in home environment
• Need more information on technology and equipment available
• Person with dementia needs to have access to support to go to activities and families need the time to have a break from caring responsibilities
• Person with dementia needs support to remain at home while family members are out (VERY IMPORTANT).

What does SDS mean at the advanced stages of dementia?
• Assessments at every stage as dementia progresses
• Flexibility to increase support from services to keep carer healthy & supported as well as stimulating the person with dementia
• System lets carers down – System needs to change – Improve the system
• Educate carers regarding services available ask about what is available
• To have known about SDS before the advanced stages
• More funding available for care within the home!
• More control of care EMPOWERS
• Hospital to nursing homes (not always appropriate).
Improvements we want

Social Services
- Timing the involvement of support
- Having peer support
- Information pack with resources
- Available Information
- Want some support and guidance from SWD
- Provide more Training to frontline staff.

Health Services
- Limiting waiting times between specialist appointments
- Conflict of information being given between Government & NHS
- Follow-up appointments following diagnosis from CPN etc
- Provide more training to front-line staff
- Give same service that people with diabetes etc…monitoring, advice, support, information – not left alone to cope
- Give information about Alzheimer Scotland and SDS.

Help to Maintain Lives & Natural Supports
- Fairness in supporting the carers
- Person supporting the person being cared for are better at getting other help for the individual
- Access to carers need of information/respite
- Community involvement / resources
- Community planning & supporting communities
- Enabling people to feel comfortable within their environment
- Supporting personal interests
- Enabling people to maintain dignity throughout
- Independence
- Risk enablement for individuals
- Have more positive publicity on Dementia
- Positive models to inspire others
- Support the person with dementia and family to go through the process
- Process currently via care manager
- Use of assistive technology to help maintain independence (can ask LA for assessment of need)
- Person with dementia must want support
- Thinking creatively
- Respite at home
- Supported holidays for person with dementia
- Small budget for ‘Buddy’ for social/leisure
- Information on state benefits – Income maximisation –(LA/DWP)
- Information to empower (booklet, someone to talk to)
- Importance of GP signposting to agencies/services that can help provide information
- Need to reduce stigma
- Alternatives to Long Term Care
• Flexible working hours needed
• Accessing money quickly as debt causes further stress
• Younger people can be overlooked
• Younger people can be natural peer educators
• Many local networks out there and could be used to raise awareness
• SDS should be used to enable family and carer to continue to lead “usual life”
• Have a fund to pay someone you know or pay expenses rather than pay a stranger
• Funding to meet personal outcomes
• Acknowledge the support that is given by families
• Preference for a family group to care for some
• Importance of faith
• Natural supports can last longer
• Using internet and libraries.

Planning Future Care & Support
• Different types of dementia require different types of assessment
• Evaluating services regularly
• Continuum of positive guidance & Support
• Advance directives at early stages
• Addressing Power of Attorney & Wills
• Limit to red tape – simple information for people to understand
• Personalise care to the individual needs
• Carers to be informed of details in assessment
• Support should be person centred
• Help to build confidence and develop knowledge of SDS
• Option for follow up contacts – weeks/months later when Person with
• Dementia wants/is ready for information – someone knowledgeable
• Role of dementia specialists nurses/Macmillan model of developed
• Using new technology – how to find it
• Family members could take on more
• Encourage to do what person wants = full life
• Don’t turn home into an institution
• Timing issues – even being in time to shower someone can be hard work
• Importance of Power of Attorney
• Importance of recording needs/wishes of person with dementia/memory book
• Importance of making decisions for future
• SDS as Enabler
• Alzheimer Scotland hitting the ground running with information and dementia
  advisors - must bring other on board
• Carers/Professionals can take over and speak for person with dementia when they are
  able to talk for self
• We need support earlier – needs not always seen as “support”
• SDS should enable individual support arrangements and avoid “block booking”
  service
• The Quality of care is important
• A life of adjustment and we are adjusting but need help to educate others
• Go by what I do – not what I say
• You would get a better assessment by watching the individual rather than a verbal assessment
• Monitoring important
• People must know what they are entitled to – how much they can get
• Carers must have a life too
• Carers often “take up slack” and provide a lot of “hidden support”.
Appendix 2 - Questionnaire responses

39 responses

1. Had you heard about SDS before the event

   23 had heard of SDS; 16 had not.

2. If yes, how found out about it

   9 heard of it through voluntary sector agencies.
   5 had been informed by their social worker or health professional.
   6 had professional awareness.
   1 found out through Internet search on dementia, 1 seen it advertised and 1 found out through a SG consultation event.

3. Do you know what direct payments are

   21 knew about direct payments.
   9 did not know about it.
   9 were not sure.

4. If yes, how found out about it

   7 found out from social work or health professional.
   7 found out from a voluntary sector organisation.
   3 knew about it professionally.
   2 found out through SG consultation event.
   1 knew a friend who received it.
   1 non response to question.

5. Used a direct payment

   Only one respondent had used a direct payment.

6. Reason for coming along

   11 wanted to find out more about SDS.
   3 wanted to find out more about direct payments.
   3 wished to give their views on the development of SDS strategy.
   1 came along to provide support.
   21 had more than one reason, including finding out more information and giving their views on the development of the SDS strategy.

7. Additional comments

   There is no information on the stage SDS or direct payments would be applicable. At beginning of this process; will be discussing SDS with social work to establish this from the outset.
GPs and care teams should be engaged with the feedback from this process so it is not lost.
Need for more information to be made available to the public.

8. About you

5 people with dementia.
21 carers (or former carers).
6 professionals.
3 friends of person with dementia or carer.
4 non responses.
Appendix 3 - Evaluation form responses

37 responses

1. Reason for coming along

30 came along to find out more about SDS, direct payments and other information for people with dementia.
3 professionals came to support.
4 came to gain information to pass onto their colleagues and/or organisation.

2. Have your reasons been met

25 felt their reason for coming along had been met.
12 felt it had been partially met.

3. What would you like outcome of today to be

Better information, easier access to support, for people to be treated as individuals, more people being able to access direct payments, comprehensive guide for carers and professionals, SDS widely available and understood
Feedback from today to be taken back to appropriate people, so that positive action is taken; information from today being acted on by the Scottish Government

4. About you

4 people with dementia.
22 carers.
6 professionals.
1 friend of person with dementia.
4 non responses.