

19 March 2025



# Building Better Pathways

Improving Access to Self-Directed Support for  
People Living with Dementia

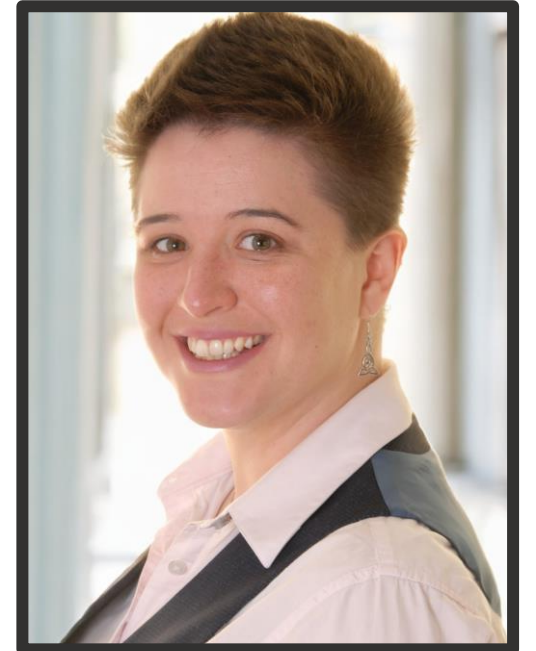
*Dr Catherine Pemble*

# An Introduction

Catherine Pemble is a social scientist based at the University of Stirling in Scotland. Her research explores the intersection of disability and dementia studies, with a particular focus on improving the lives of people living with long term disability and cognitive impairment. She has worked on a variety of projects including:

**The Changing Intergenerational Relationships Project:** Part of the Connecting Generations Centre, this project is a regional case study exploring the different ways in which intergenerational relationships can shape and be shaped by issues around changing working practices, digital poverty, access to health and social care, and intergenerational living.

**The Designing Homes for Healthy Cognitive Ageing Project:** A UKRI Funded project examining how peoples' homes can be built or adapted to better support them as they age.



# General Barriers to SDS

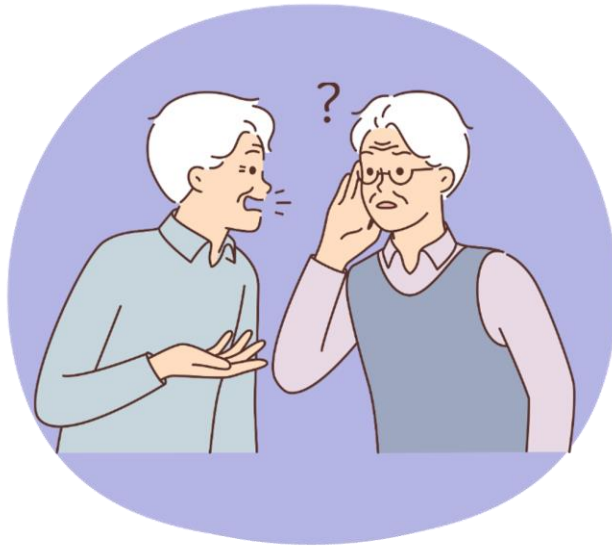
While SDS principles *should* naturally align with Scotland's person-centred approach to supporting older adults, as outlined in initiatives like Reshaping Care for Older People (2011-2021) and A Fairer Scotland for Older People (2021), there are a number of barriers for those wishing to access SDS including:

- SDS has been introduced inconsistently across Scotland, with little evidence of the widespread changes needed to deliver its full potential<sup>1,2</sup>
- There's limited evidence to show how well SDS processes give people choice and control over their care, or support them to reach positive outcomes<sup>2</sup> or how intersectional factors impact people's experiences of SDS<sup>3,4</sup>
- Guidance on the processes around accessing and using SDS is often lacking, leaving many to rely on independent or third-sector organisations for help.
- Despite being directed to shape care plans through 'good conversations'<sup>5</sup>, social workers often struggle to distinguish between co-design (actively involving users in shaping their care) and consultation (asking for opinions)<sup>6</sup>
- Many SDS users report being actively steered towards Options 1 and 3, which mirror traditional care packages, with only 42% informed about all four SDS options<sup>4,7,8</sup>



# Barriers to SDS for People Living with Dementia

This report brings together insights from a range of sources including, the Scottish Government, the Care Inspectorate, Audit Scotland, the Alliance, SDS Scotland, and academic research to explore three key areas where people living with dementia face additional barriers to accessing SDS.



Attitudes and Beliefs



Navigating the System



SDS in Practice

# Attitudes and Beliefs around Dementia

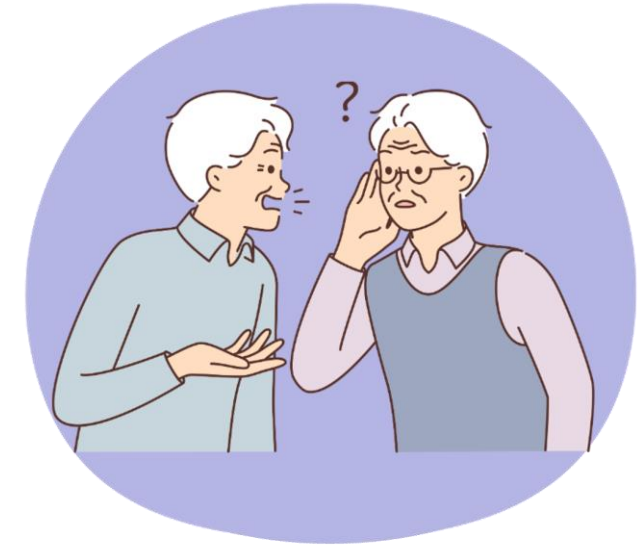
Despite growing efforts to promote 'dementia awareness' and 'dementia-friendly' initiatives in Scotland, many people living with dementia still face stigma from the general public and professionals<sup>9,10</sup>

Public understanding of dementia remains limited, with little awareness of the different types of dementia or how symptoms can extend beyond memory loss to include issues with planning, communication, emotional regulation, literacy, numeracy, or executive function<sup>11</sup>

Additional challenges appear for those with rarer forms of dementia or symptoms that don't fit stereotypes<sup>12,13</sup> such as disabled people, queer people, people from BME communities or people with young onset dementia

People living with dementia are often assumed to lack capacity post diagnosis<sup>14</sup> and expected to receive unpaid care and support from others in their life

Disability and dementia are often viewed, and approached, separately-creating ongoing issues around the use of the medical model



# Principles of Self-Directed Support

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<b>Collaboration</b>	Individuals are supported to achieve better outcomes in their lives
<b>Dignity</b>	A person's right to dignity is facilitated throughout the support they receive
<b>Participation</b>	Everyone has the right to participate in decisions which affect their lives. Therefore, people are supported to participate freely and equally in their community and wider society
<b>Involvement</b>	Co-production enables people to be involved in a genuine and active way at all stages of their support, to be supported to know their rights; to participate in the development of local policies and practices; to articulate their personal outcomes and to plan, manage and deliver their support; and play an active part in their communities
<b>Informed Choice</b>	People are supported to make informed choices based on impartial information about their eligibility for support, the choices available to them and their aspirations
<b>Innovation</b>	People are supported to develop creative and flexible solutions in order to meet their personal outcomes
<b>Risk Enablement</b>	People are empowered and trusted to set the parameters of their own risks and make the choices which will impact on their lives
<b>Responsibility</b>	People are supported to take responsibility for the choices they make and the control they take over the activities to meet their agreed outcomes



# Navigating the System

*(You've decided to apply for SDS... now what?)*

Evidence from the My Support, My Choice study indicated that 43% of people learned about SDS from a social work professional or occupational therapist, with another 6% hearing about SDS through the NHS – meaning 50% people who learn about SDS do so through other channels<sup>4</sup>.

Independent Support Organisations (ISOs) are a crucial part of the SDS ecosystem, often providing information, advice, and advocacy for those seeking to access Self Directed Support- with as many as 71% of MSMC respondents agreeing that ISO support made SDS easier to navigate<sup>4</sup>.

Ongoing efforts to support the work of ISOs include large Scottish Government funded initiatives like the Support in the Right Direction programme, which has received 9.3 million since 2018 to support ISOs in 32 organisations across Scotland<sup>17</sup>.



# Navigating the System

*(You've decided to apply for SDS... now what?)*

## Advocacy

Advocacy Orkney, Advocacy Service Aberdeen, Advocacy Western Isles Eilean Siar, Circles Network Advocacy, Equals Advocacy, The Advocacy Project, Equal Say

## SDS Advice

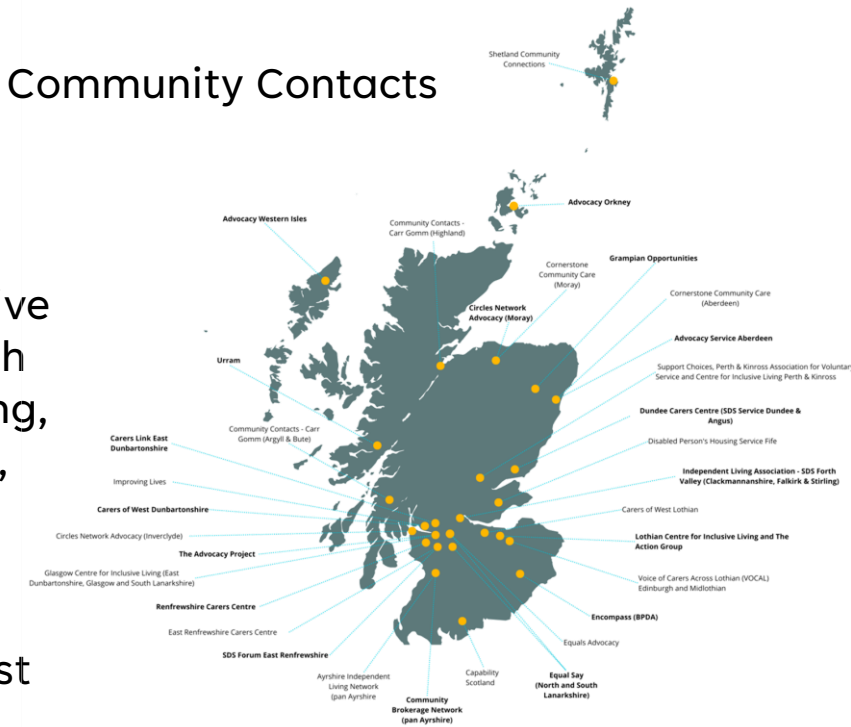
Borders Direct Payment Agency (Encompass), Lothian SDS Forum, Carr Gomm Community Contacts

## Housing & Living

Ayrshire Independent Living Network, Disabled Person's Housing Service Fife, Cornerstone Community Care, Capability Scotland, Glasgow Centre for Inclusive Living, Lothian Centre for Inclusive Living, Independent Living Association Forth Valley, Support Choices, with partners PKAVS and the Centre for Inclusive Living, The Community Brokerage Network, Grampian Opportunities, Improving Lives, Urram, Shetland Community Connections

## Carer Services

Carers Link East Dunbartonshire, Carers of West Dunbartonshire, Carers of West Lothian, East Renfrewshire Carers Centre, Renfrewshire Carers Centre, The Disabled and Carers Information Centre, VOCAL (Voice of Carers Across Lothian)





# Navigating the System

*(You've decided to apply for SDS... now what?)*

While ISOs supporting access to Self Directed Support may be able to provide specific insights for people living with dementia, it's unlikely they would be able to do so in a consistent or reliable way.

The diverse experiences and symptoms of people living with dementia, combined with the lack of clarity around the ways in which SDS is applied across regions introduces significant issues when attempting to navigate SDS alongside someone living with dementia.

These boundaries may be further compounded by barriers within dementia services, which can lead young, queer, disabled, or BME people living with dementia to choose to avoid engaging with 'traditional' dementia support spaces- potentially reducing exposure to SDS information through ISOs. While differences in religious beliefs and cultural practices may introduce additional barriers to seeking support through health care routes <sup>18,19</sup>



# SDS In Practice

While the Independent Review of Adult Social Care in 2021 called for Social Workers and Health and Social Care Partnerships to focus on the rights of potential SDS users instead of the costs, it also acknowledged that the current system was reactive, rather than proactive, and driven by the need to cut costs rather than improve outcomes.

This presents issues for older people, and particularly people living with dementia who might wish to use SDS. Research with social workers highlighted an ongoing resistance to suggesting options involving direct payment, linking it to early restrictions around Direct Payments which rendered people over 65 ineligible.

While later legislation removed the restriction on direct payments, people over the age of 65 often find their awards capped at a lower amount, often linked to the cost of nursing home placement<sup>20</sup> despite SDS being *theoretically* available to those living in residential care<sup>21</sup>

Further evidence suggests a separation between teams involved in home care and those involved in SDS, with referrals to SDS often only happening when a person's needs became 'too complex' for home care teams<sup>22</sup>



# SDS In Practice

Despite SDS creating opportunities for more flexibility<sup>23</sup>, different SDS options may present challenges for people living with dementia, including:

Professional resistance to offering SDS options like Direct Payments<sup>24,25</sup>

The impact of issues with numeracy, literacy, memory, or executive function on practical aspects of managing direct payments and budgets<sup>26</sup>

Real or assumed challenges of recruiting and managing staff, or employing family members<sup>27,28,29</sup>

Need for both formal and informal support to manage SDS options<sup>30</sup>

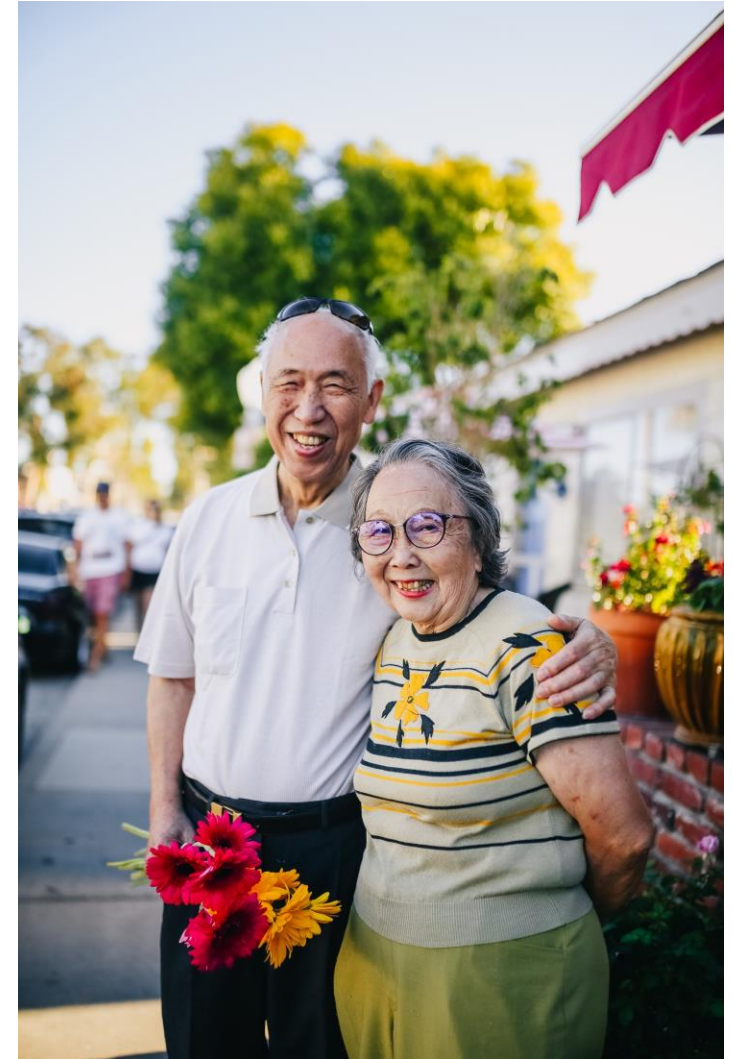
Tensions between enabling principles of SDS, and the cost-focused, risk-averse practices of professionals<sup>31</sup>



# Vignette

Rose is a 72-year-old artist who was recently diagnosed with early-stage dementia. She's determined to stay active and continue painting, which brings her joy and a sense of purpose. However, she's worried about losing her independence and being steered towards traditional care options like day centres, which don't align with her interests.

Rose tells you that while the 'slips' in her memory are irritating, she's more concerned by her issues counting and keeping track of money and "people always assuming my family are my carers!". She wonders about whether Self-Directed-Support might be the right for her and asks for your advice.





# Recommendations and Next Steps

- Advocate for review of materials and greater access to easy-read materials, facilitated communication strategies for those looking to explore SDS.
- Advocate for all Local authorities to publish their eligibility framework as a matter of course, following South Lanarkshire's example.
- Lobby for demographic data including dementia diagnosis to be included and published as part of wider SDS data to improve transparency.
- Advocate for meaningful dementia awareness & SDS training for social work and healthcare professionals.
- Identify potential interventions to support a shift in social work language from risk-focused to empowering.
- Advocate for further investigations into 'good practice' examples of people living with dementia using SDS.

# Thank You!



*Any Questions?*

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