Delivering high-quality Post Diagnostic Support

Supporting the delivery of high-quality, person-centred Post Diagnostic Support (PDS) is a priority for both the Scottish Dementia Working Group & National Dementia Carers Action Network. The SDWG is committed to: “Campaigning for improved, dedicated PDS & support pre-diagnosis to meet people’s needs.”

Meanwhile NDCAN has pledged to focus on: “Continued support for the delivery of high-quality post diagnostic support that is individualised, extends past the one year commitment, and is available not only to those living with dementia, but their carers too.”

Group members were pleased to be able to meet recently with Maureen Taggart and Nikki Lorrimer, Alzheimer Scotland’s Executive Lead and Associate Executive Lead for PDS, who outlined how Alzheimer Scotland is commissioned to work in 10 Health Board areas across Scotland, with over 100 PDS Link Workers helping to deliver on the Scottish Government’s promise that every person with a new diagnosis of dementia in Scotland is entitled to a minimum of one year of PDS from a named person.

In addition to finding out about the numbers of people supported by Alzheimer Scotland Link Workers, 4,494 in the first quarter of 2023, group members explored issues around the quality of support offered and the added benefits they bring, such as the Dementia Resource Centres and Advisors, community groups and national services provided by Alzheimer Scotland.
Members discussed with Maureen and Nikki the single quality question introduced by Alzheimer Scotland to measure the helpfulness of the support provided; they sought more information on the framework used by the organisation to ensure high-quality PDS is delivered; and they explored the training and development that Link Workers benefit from so that they can provide the best, person-centred support to meet individual needs.

Members spoke about work that they had been engaged in previously to create a resource to help people make the most of their PDS, and were pleased to learn that Alzheimer Scotland continues to use this tool. The Groups welcomed information from Maureen and Nikki about additional work they are involved in, including around pre-diagnosis, power of attorney, person centred plans, and Specialist Dementia Carer Support Link Workers. Both groups have a long-standing concern about the ‘post code lottery’ of service delivery across Scotland and are keen to see consistent high-quality PDS delivered by a named person, regardless of the organisation providing the service.

Members also want to see better quality data captured by the Scottish Government, so that they know what is working well, what needs to improve, where services are needed, and what funding is required. SDWG and NDCAN members will continue to campaign for and raise awareness of these important issues.