



Carers' Centre Mapping Project Scotland

A report by the Neurological Alliance of Scotland

March 2023

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Introduction:

Scottish Government estimates that there are more than 800,000 unpaid ¹carers in Scotland, which has a population of 5.5 million. We are currently living in a crisis, where unpaid carers are recognised as supporting the very backbone of society, with the economic value of unpaid care in Scotland estimated to be £13.1bn per [year](#).² However, despite relying on unpaid carers, the systems set up to support them are complex and time-consuming.

This is particularly so for those who care for people with a neurological condition. Supporting someone with a neurological condition can be particularly challenging for unpaid carers. Conditions that impact the brain, spine and nervous system are very varied, and can have a wide range of impacts. Many conditions are poorly understood and have limited treatments. Access to care and support can also be very complicated and services are often lacking.

The Scottish Government is over halfway through its [Neurological Framework for Action 2020-2025](#). The Framework's [commitment 3](#) refers directly to supporting unpaid carers of people with neurological conditions.

“Local carer information and advice services know how to access the most relevant information and training for carers of people with neurological conditions.”

The Neurological Alliance of Scotland was commissioned by Scottish Government to engage with Carers' Centres to understand what information and advice, as well as training, is given to people caring for those with a neurological condition at Carers' Centres across Scotland. Our report provides a starting point, helping to understand what information and services Carers' Centres across Scotland provide for those caring for someone living with a neurological condition.

At the end of our report, we make several recommendations for further action. We note however that the current financial crisis means that charities and Carers' Centres are already operating at or beyond maximum capacity and unless further actions are funded, they are likely to remain as a wish list of recommendations.

The Scottish Government published its renewed National Carers' Strategy in December 2022 which covers activity in social care up to 2026. This strategy recognises the differences in burden placed on carers of people with progressive or terminal illness which includes certain neurological conditions. The National Carers' Strategy also [promises](#) action for carers of people with neurological conditions:

“We will work with the NHS boards, integration authorities, neurological and carer organisations to help ensure carers of people living with neurological conditions are aware of their rights under the Carers Act; and that local carer services know how to access the

¹ <https://www.gov.scot/policies/social-care/unpaid-carers/>

² <https://www.gov.scot/publications/national-carers-strategy/pages/2/#:~:text=Unpaid%20carers%20make%20a%20huge,%C2%A313.1%20billion%20per%20year.>

most relevant information and training for carers of people living with neurological conditions.”

Our report is in two parts. It looks at how neurological charities specifically address services and the information support needs of carers, as well as how Carers’ Centres support people caring for someone with a neurological condition and their interactions with neurological charities.

About the Neurological Alliance of Scotland

Established in 2004, the Neurological Alliance of Scotland is a membership organisation now comprising over 50 neurological charities and voluntary organisations who work with people with a neurological condition. The majority of our members are single-condition charities who collectively cover 25 neurological conditions. We also have several member charities which are generalists, covering all neurological conditions. We work to improve the care and support that people receive. We have a broad reach, with the majority of our organisations based in Scotland. Over a third of our members are headquartered in England and offer services or outreach in Scotland.

You can find out more about us at: <https://www.scottishneurological.org.uk/>

Timeframe for the project:

| Date | Action |
|-------------------------------|---|
| 9-13 January 2023 | Design the two questionnaires and build list of Carers’ Centres in Scotland |
| 16-20 January 2023 | Finalise questionnaire with colleagues from Carers’ Centres |
| 23 January – 10 February 2023 | Fieldwork – all Carers’ Centres in Scotland are invited to respond |
| 13 February – 3 March 2023 | Analysis of results and report writing |
| 6-10 March 2023 | NAoS Executive review of report |
| 13 March 2023 | Publication of report |

Respondent Information

Our remit was to survey Carers’ Centres, but in order to get more of a 360 degree view of the situation, we also issued a survey via googledocs to our member charities to see how they work with Carers’ Centres and what support, activities and information is provided directly to unpaid carers. We had a 43% response rate (n=23). 48% of NAOs respondents were from UK-wide charities, 34% were from Scotland-wide charities and 17% were from charities operating locally within Scotland. A list of NAOs respondents and their locations can be found in Appendix A.

The Carers’ Centre survey was issued via Survey Monkey to 66 Carers’ Centres across Scotland. We received 39 responses, of which 5 appeared to be duplicates and which were therefore removed, taking our total respondent base to 34 (52% of the total number of Carers’ Centres we approached). Respondents include both adult and young Carers’

Centres.

Fieldwork for both surveys was open for three weeks, from the 23 January – 10 February.

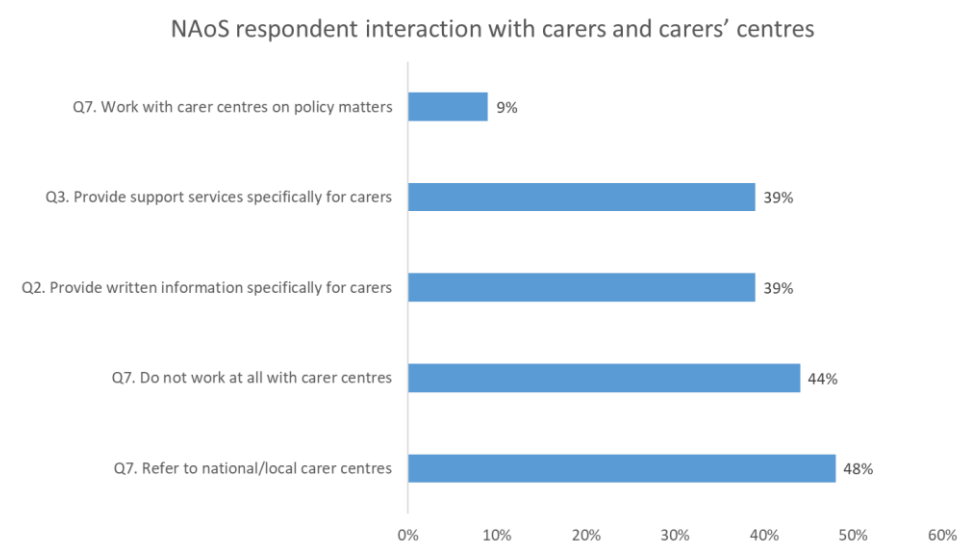
Respondent Table

| Survey title | Audience | Response rate |
|--|-----------------|--------------------------|
| How NAOs members interact with Carers' Centres | NAOs members | N=23 / 43% response rate |
| Via googledocs | See Appendix E | |
| Carers' Centre Survey | Carers' Centres | N=34 / 52% response rate |
| Via Survey Monkey | See Appendix F | |

A list of NAOs members who participated in the research, and their locations can be found at Appendix A and a list of Carers' Centres who participated in the research, and their locations can be found at Appendix B.

Part 1: How do neurological charities support carers and interact with Carers' Centres?

A list of the questions we asked NAOs Members can found in Appendix E.



Provision of information and support

Naturally, the primary focus of neurological charities is to provide information and support to people living with that condition. The majority of our members are single condition focussed and are experts in that condition. When asked whether they provide printed and / or online information for unpaid carers, only 39% confirm that they do.

However, some of the charity websites of some of those who didn't click this option do have carer's pages, so we would caution against using 39% being the actual proportion of NAOs respondent charities with carer specific information.

Another 39% provide information that is suitable both for people with a condition and their carer and 9% provide information that is specifically intended for the person with the condition.

So, collectively, 78% of our members provide supportive **information** that's either targeted at carers, or which is aimed at people with a condition, but which is suitable for carers to read.

A full list of the online or print carer resources provided by NAOs charity respondents can be found in Appendix C.

In terms of providing specific support or activities, just 39% of respondents consider themselves to provide support specifically for unpaid carers, but when asked to provide more detail, that rose to just under half (48%) of our members who listed information about the support they provide as support specifically for unpaid carers. Support activities include helplines, peer support groups, counselling and family & friends events.

Another 35% of NAOs respondents provide support and activities that both the person with the condition and unpaid carers can access. 17% limit support and activities for those with the condition only, and 9% do not provide direct support activities at all.

So, collectively 74% members say they provide **support activities** that carers can join, either independently of the person they care for, or together with them.

Three quarters of NAOs member respondents who don't currently provide services or information for unpaid carers (73%) see value in developing these sorts of resources and are interested in developing resources and activities for carers in the future (Q6).

A list of the carer support activities provided by NAOs charity respondents can be found in Appendix D.

Referrals

35% of NAOs member organisation respondents refer people to local Carers' Centres, and 13% refer to national carer organisations. 9% of our members work more directly with national Carers' Centres on policy and rights issues. 44% of member respondents do not currently work with carer organisations in Scotland (Q7).

Part 2: How do Carers' Centres support those who care for people with neurological conditions?

Background

In 2021 the Neurological Alliance of Scotland published three guides to help people care for those with a neurological condition ([What to expect when you are new to caring](#), [What to expect from advocacy services](#) and [What to expect when planning ahead](#)). In 2022 we published [three factsheets](#) to help people with neurological conditions and unpaid carers to access self-directed support.

However, this was the first time in the past two years that we have had direct outreach with individual Carers' Centres across Scotland. We were pleased with such a high response rate for this project, which is to be credited to dedicating time emailing and calling each individual Carers' Centre, and thanks must also go to the Coalition of Carers in Scotland who supported our research project by encouraging their members to participate.

Carers' Centre Questionnaire

The Carers' Centre questionnaire was kept deliberately short in order to be manageable and of the 10 questions, only two were open ended. This means that the results we received are very much to be seen as a top-level overview and we would recommend that longer qualitative interviews are done as a follow up, to explore specific areas in more detail.

We understood in preliminary emails with the Chair of the Carers' Centre Network, that some Carers' Centres use a system called CharityLog. This does not register individual neurological conditions but registers whether a person is looking after someone with 'dementia', or a 'non-dementia neurological condition'. As a result of this feedback, we removed the list we had planned to use, of 30 or so more common neurological conditions, and in Q6 we only asked for splits by dementia / non dementia neurological conditions. Whilst we know anecdotally that 100% of Carers' Centres see people who care for those with dementia, in our survey, 68% of Carers' Centres listed dementia as the **primary condition**, with 15% saying 'other neurological conditions' were the primary reason for carers coming to their centre.

One Carers' Centre replied "[We support a significant number of carers of both types. There is not really a primary group.](#)"

This data capture raises an interesting point about successive governments' political prioritisation of improved carer support for those supporting someone with dementia. [Alzheimer Scotland estimates there are 90,000 people living in Scotland with dementia](#) currently, with these numbers set to grow as our population ages. Understanding whether carers are there for either 'dementia' or 'other neurological conditions' does not allow us to paint a picture about the gaps in care support provided to the full range of neurological conditions. Yet it shows the importance to Carers' Centres in tracking the number of dementia carers they support.

There is perhaps something to be learnt for other neurological services here about what has happened to dementia services to improve support for carers with other neurological conditions and links to Carers' Centres and other resources.

12% of Carers' Centres said they supported 'other' conditions, and referenced neurodevelopmental conditions including autism and ADHD, but epilepsy and MS were also spontaneously mentioned.

The absence of collected data about neurological conditions makes it hard to draw conclusions about the extent to which unpaid carers of people with neurological conditions other than (or in addition to) dementia access Carers' Centres. We would recommend that any future work in this area should include consideration of how to overcome this data gap.

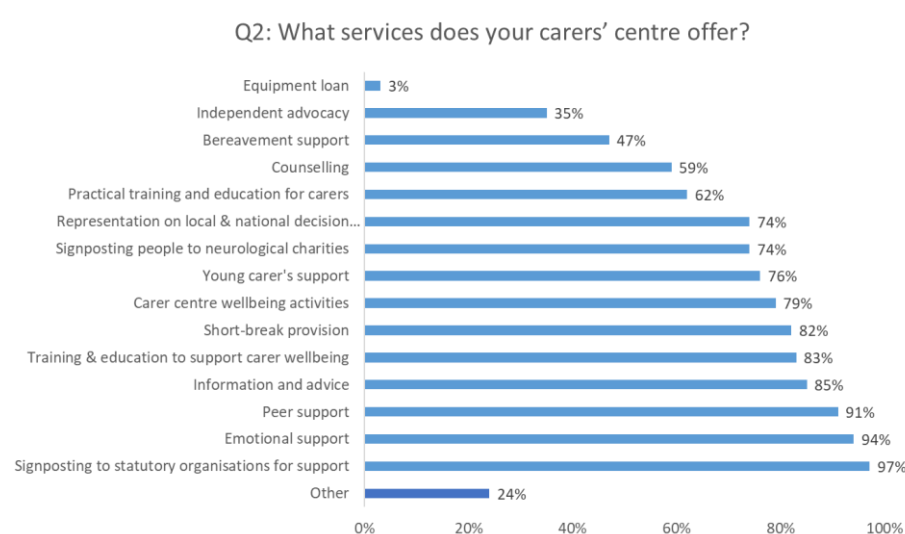
The list of the questions asked in the Carers' Centre survey can be found in Appendix F.

Services offered by Carers' Centres

The data presented here includes dementia and neurodevelopmental conditions.

Nearly all Carers' Centre respondents (97%) signpost people to statutory organisations for support, with three quarters (74%) signposting people to neurological charities. Emotional and peer support rank at the top of the services commonly offered across the board by Carers' Centres.

Of particular interest to us, is whether centres offer practical training and education for carers. Here we can see that 62% of Carers' Centre respondents do offer this, however it is not specifically related to supporting challenges commonly associated with neurological conditions (for instance, swallowing, communication issues, pain, cognitive changes etc).



24% noted that they provide 'other' services, and mentions here include: providing people with adult carer support plans, help with self-directed support, providing training both to third sector and statutory organisations on how to identify a young carer, one to one information advice and support and informal advocacy. One centre runs a pre-school playgroup for children with additional support needs and has a Sensory Room which can be hired out to carers and other organisations.

Education and training to specifically support neurological conditions

We explored the issue of education and training specifically to support someone living with a neurological condition in Q7 where we asked "Do you currently provide staff or volunteers

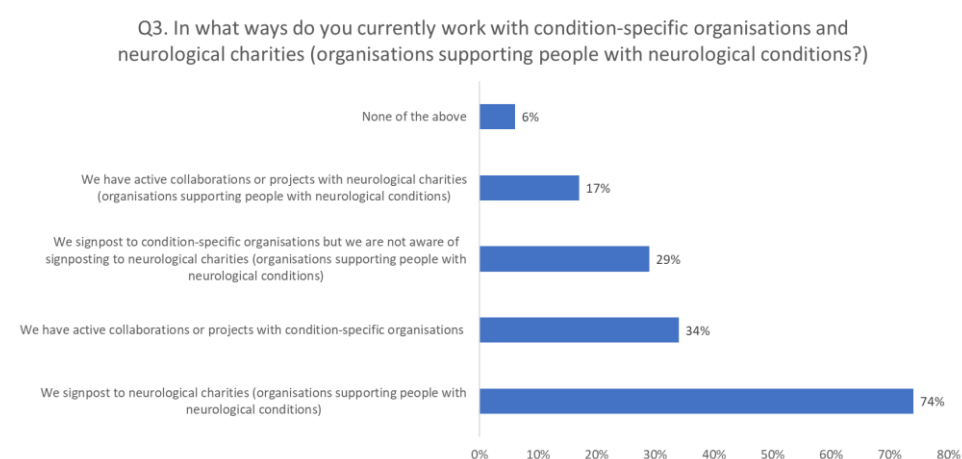
with training on important issues that can make caring for people with neurological conditions particularly challenging? (e.g communication issues, swallowing, thinking problems, mental health issues, behavioural changes, pain, physical impairments, seizures.)?”

As the chart below shows, only 21% of Carers’ Centre respondents provide training specifically related to neurological issues, although this is most likely to be related to dementia. Over a third of respondents would be keen to provide training specifically to support caring for people with neurological conditions in the future.



Signposting to the neurological third sector

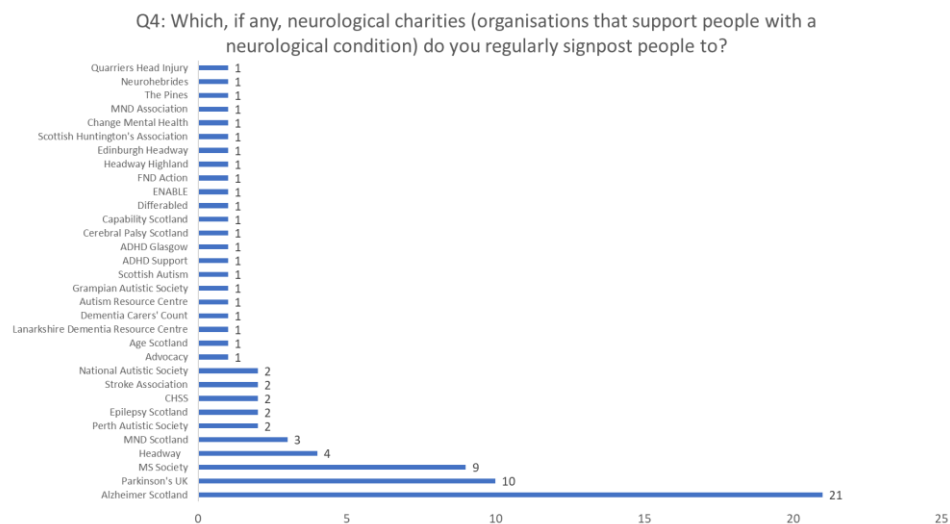
Looking in more detail at the ways in which Carers’ Centres work, 74% regularly signpost carers to neurological charities and other condition-specific organisations. This suggests a good level of confidence in directing people to organisations that can specifically support different conditions.



Below is a chart of the spontaneous mentions, where Carers' Centres name the charities they refer people to. We can see that the charity which is most often signposted to is Alzheimer Scotland, which reflects the fact that dementia is the primary neurological

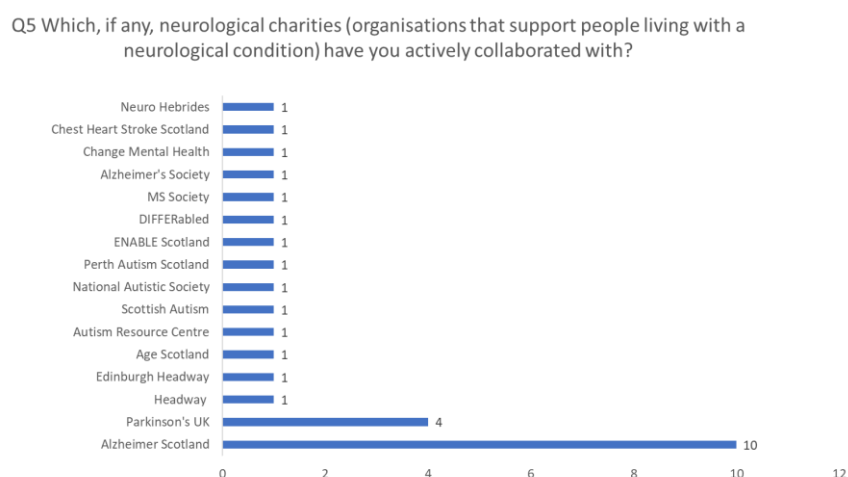
condition that Carers' Centres support. Parkinson's UK, the MS Society and Headway are the next three most signposted charities by Scottish Carers' Centres.

Referrals to dementia organisations were mentioned far more often than for any other condition - organisations supporting dementia were mentioned 21 times, compared with 10 for Parkinson's, 9 for MS, 9 for autistic spectrum disorder and 7 for head injury.



Active collaborations with neurological charities

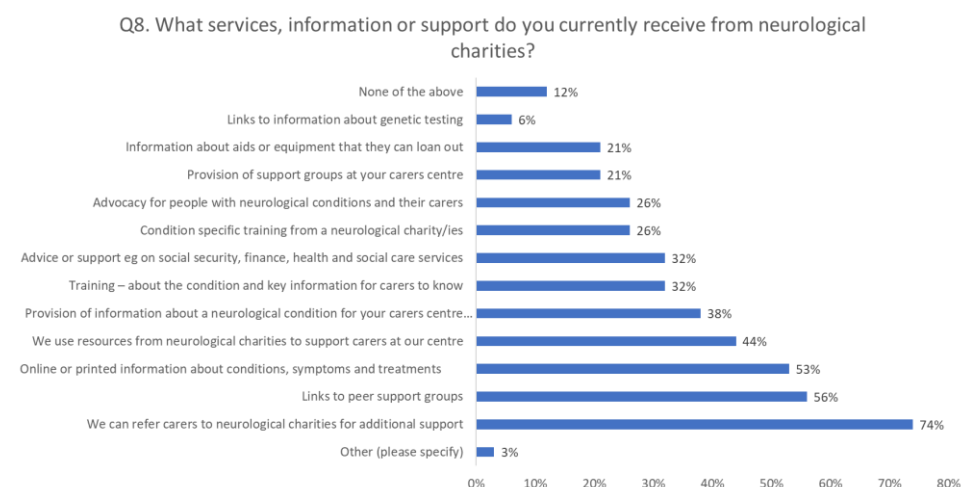
As we saw above in Q3, 18% of Carers' Centres agreed that they have active collaborations with neurological charities. The majority of collaborations mentioned in Q5 are with Alzheimer Scotland. Parkinson's UK and Headway also receive multiple mentions.



Support currently received from neurological charities

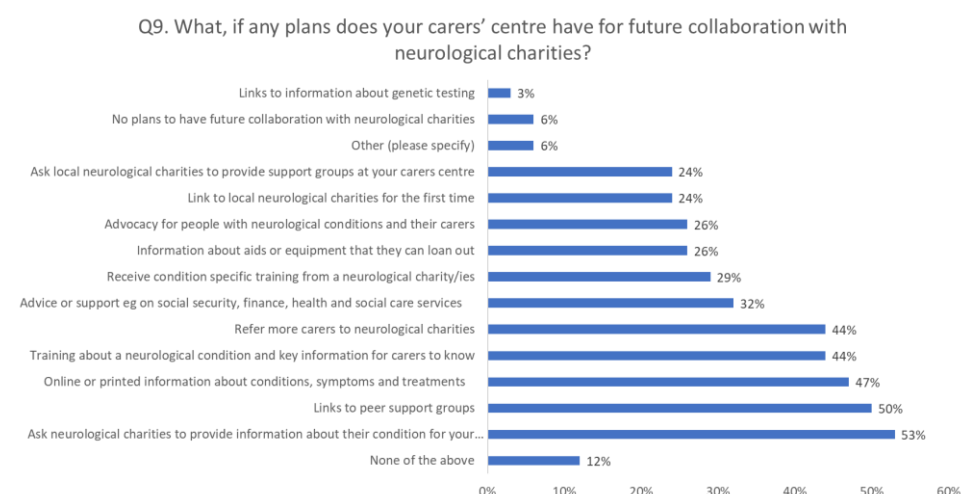
In Q8 we explored what services, information and support Carers' Centres receive from neurological charities. 12% said they received none of the options we provided in the survey. However, the majority of Carers' Centres receive a good range of support from neurological charities with 74% saying they can refer carers to neurological charities, 56% can link their carers to peer support groups run by charities, and 53% access online or printed information about conditions, symptoms and treatment from neurological charities. 32% of Carers' Centres receive training and key information for carers to know from

neurological charities about the condition. 21% of Carers' Centres provide peer support groups run by charities at their centre.



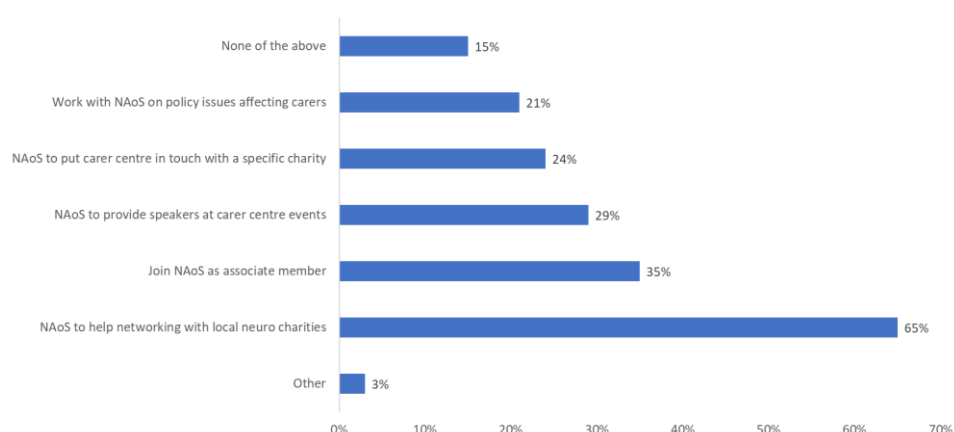
Support Carers' Centres would like to receive from neurological charities

When we compare what Carers' Centres currently receive from neurological charities (in Q8) and what they'd like to receive (in Q9), the top two asks are for more information about conditions to be distributed to Carers' Centres (53%) and for more charities to provide links to peer support groups (50%). 47% of Carers' Centres would like online or printed information about conditions, symptoms and treatment and 44% would like to refer more carers to neurological charities. 29% of Carers' Centres would welcome training from neurological charities about a neurological condition and key information for carers to have. The vast majority of Carers' Centres are open to more collaboration with neurological charities.



Our final question to Carers' Centres was to ask how the Neurological Alliance of Scotland can support the aims of Carers' Centres for future collaboration with neurological charities. Support with networking was the biggest ask at 65% and just over a third of respondents said they would like to join NAOs as associate members.

Q10. How can we, the Neurological Alliance of Scotland (NAoS), support your aims for future collaboration with neurological charities?



Conclusion:

This scoping research has enabled us to start to understand how local Carers' Centres and neurological charities in Scotland are supporting unpaid carers of people with neurological conditions. We have achieved our primary aim of gaining some quick insights from a reasonable number of respondents, without being burdensome to either sector.

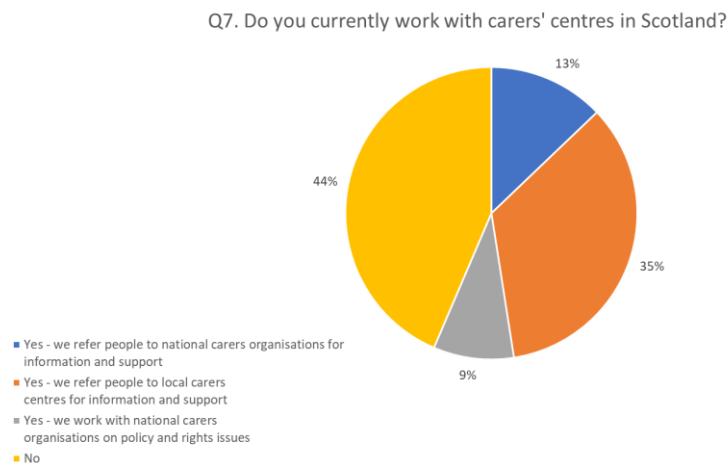
Based on the information we received, we have been able to make some recommendations and suggest opportunities for future work.

Whilst what we have discovered is reassuring, we note that much more can be done. Across Scotland, Carers' Centres are already highly likely to be referring carers to condition specific charities including neurological charities. General training and education rank highly on the list of their services. But we believe that more can be done to support people caring for those living with a neurological condition.

There is appetite for greater engagement between the sectors. 73% of our member respondents who don't yet provide specific information or support activities for unpaid carers want to develop these in the future (Q6 NAOs questionnaire), and 94% of Carers' Centre respondents are interested in future collaboration with neurological charities (Q9 Carers' Centre questionnaire – only 6% say they have 'no plans'). It is possible that there is a role for the Neurological Alliance of Scotland to act as a conduit in building relationships between our members and Carers' Centres.

We have seen from our members' survey that under half (44%) of NAOs respondents do not currently work with Carers' Centres at all (see pie chart for Q7). Scottish Council for Voluntary Organisations (SCVO) reports that 61% of voluntary organisations are experiencing financial challenges in the face of increased demand for services, and many neurological charities simply do not have the capacity to take on additional unfunded work at this time. We know that for some organisations, it may not be possible to develop work with Carers' Centres at this time - even if they believe that it would be a valuable area of work for them and the community they support.

From the Carers' Centre survey, we note that charities that deal with Alzheimer's, head injury, Parkinson's and MS are the most likely to be signposted to. In order to widen the scope of neurological charities that carers can be referred to, we would like Carers' Centres to understand more about other neurological conditions and the charities that support them.



Recommendations

There are some immediate, medium term and long-term steps that we recommend, to ensure that people caring for anyone with any neurological condition in any part of Scotland, has access to be best information, support and service at the right time.

Short-term recommendations:

- We will share our 'what to expect' series with all Carers' Centres
- We will share our Self-Directed Support resources with all Carers' Centres
- We will repeat the invitation for Carers' Centres to join us as associate members

Medium term recommendations:

- We will compile a list of the 25 or so more common neurological conditions and list which charities offer services that support these conditions. We will distribute this to Carers' Centres who can use it to support carers looking for places to get help in supporting the person they care for.
- We will compile a list of all our member charities who have specific online resources for carers including peer support groups and distribute this to Carers' Centres to enable them to refer carers to a wider range of neurological charities.
- We will work with Carers' Centres to make sure that they have printed information about neurological conditions to make available to carers.
- We will continue to work alongside local and Scotland-wide carers' organisations and identify opportunities to reach out, providing information that could support them in their work with carers for people with neurological conditions

Longer-term recommendations

- We will include the list of Carers' Centres in Scotland on our website and will signpost our members to this information regularly
- We will build up the training provided in Carers' Centres that focusses on supporting neurological conditions, by linking condition specific charities who can provide training with Carers' Centres
- Scottish Government should consider more research to identify the information and support needs of carers via Carers' Centres so that NAOs members can build services around that

Appendix A: List of NAOs Member Respondents

| | NAOs member respondents | Location of charity / organisation |
|----|---|--|
| 1 | Action for ME | UK |
| 2 | Alzheimer Scotland | Scotland |
| 3 | Ataxia UK | UK |
| 4 | Braintrust | UK |
| 5 | Brain and Spine Foundation | UK |
| 6 | Cerebral Palsy Scotland | Scotland |
| 7 | Compass Therapy, Support, Community | Lothian |
| 8 | Dystonia UK | UK |
| 9 | Edinburgh Headway Group | Edinburgh |
| 10 | Epilepsy Connections | Greater Glasgow & Clyde, Forth Valley, and Ayrshire and Arran health board areas |
| 11 | FND Hope UK | UK |
| 12 | #ME Action Scotland | Scotland |
| 13 | MND Scotland | Scotland |
| 14 | MS Trust | UK |
| 15 | MS Society | UK |
| 16 | Multiple System Atrophy Trust | UK |
| 17 | My Name5 Doddie Foundation | UK |
| 18 | The Oxygen Works | Highland / Grampian region |
| 19 | PSPA | UK |
| 20 | Parkinson's UK Scotland | Scotland |
| 21 | William Quarrier Scottish Epilepsy Centre | Scotland |
| 22 | Scottish Post-Polio Network | Scotland |
| 23 | Scottish Tremor Society | Scotland |

Appendix B: List of Carers' Centre Respondents

| | Name of organisation | Location |
|----|---|------------------|
| 1 | Aberdeen Young Carers | Aberdeen |
| 2 | Caithness Klics Young Carers | Wick |
| 3 | Care for Carers | Edinburgh |
| 4 | Carers of West Dunbartonshire | Clydebank |
| 5 | Connecting Carers | Dingwall |
| 6 | Crossroads Care Orkney | Kirkwall |
| 7 | Crossroads Carers' Centre Cowal & Bute | Dunoon |
| 8 | Dochas Carers' Centre | Lochgilphead |
| 9 | Dumfries and Galloway Carers' Centre | Dumfries |
| 10 | Dundee Carers' Centre | Dundee |
| 11 | East Ayrshire Carers' Centre | Kilmarnock |
| 12 | East Renfrewshire Carers' Centre | Giffnock |
| 13 | Falkirk & Clackmannanshire Central Carers' Centre | Falkirk |
| 14 | Glasgow East End Community Carers' | Glasgow |
| 15 | Glasgow North End Carers' Centre | Glasgow |
| 16 | Glasgow South East Carers' Centre | Glasgow |
| 17 | Helensburgh & Lomond / Helensburgh & Lomond Carers SCIO | Helensburgh |
| 18 | Inverclyde Carers' Centre | Greenock |
| 19 | Lanarkshire Carers | Airdrie/Hamilton |
| 20 | Mid Argyll Youth Development Service | Lochgilphead |
| 21 | North Argyll Carers' Centre | Oban |
| 22 | North Lanarkshire Carers Together | Motherwell |
| 23 | North Lanarkshire Young Carers (Action for Children) | Glasgow |
| 24 | North West Quarriers Glasgow | Glasgow |
| 25 | Perth & Kinross Carers' Centre | Perth |
| 26 | Perth & Kinross Young Carers | Perth |
| 27 | Quarriers Aberdeen Carers' Support Services | Aberdeen |
| 28 | Quarriers Carer Support Service | Elgin |
| 29 | Renfrewshire Carers' Centre | Paisley |
| 30 | Skye & Lochalsh Young Carers | Portree |
| 31 | Stirling Carers' Centre | Stirling |
| 32 | Tykes Young Carers | Sutherland |
| 33 | Western Isles Community Care Forum | Harris |
| 34 | Y Sort It | Clydebank |

Appendix C: Index of carer-specific information provided by neurological charities

| Name of condition | Name of charity | Link to carer information |
|-------------------|-------------------------|--|
| Alzheimer's | Alzheimer Scotland | We provide a broad range of information that centres around rights, entitlements, living well with, info on dementia, accessing support, local and national information via our website, 24hr freephone helpline, dementia resource centres and our network of dementia advisors and other staff in localities across Scotland. |
| Brain injury | Edinburgh Headway | We provide links to any organisations that may be of use. We also provide detailed information about acquired brain injury and how to cope with challenging behaviour |
| Cerebral Palsy | Cerebral Palsy Scotland | Children (https://cerebralpalsyscotland.org.uk/get-information/children/daily-care/) Younger Children (https://cerebralpalsyscotland.org.uk/other-support/advice-from-parents/). Financial Support https://cerebralpalsyscotland.org.uk/other-support/financial-support/) We also have a 'support directory' which signposts to a variety of organisations that support people with CP and their families (https://cerebralpalsyscotland.org.uk/directories/) – so it's suitable for carers or people with CP. |
| Dystonia | Dystonia UK | We have printed leaflets and can provide digital versions in response to direct enquiries we receive. |
| Epilepsy | Epilepsy Connections | https://www.epilepsyconnections.org.uk/services/field-work/ |
| MND | MND Scotland | Welfare Benefits Support; Support Groups; Counselling; Wellbeing Grant; |
| MND | MyName5Doddie | https://www.myname5doddie.co.uk/assets/media/files/MND_Patient_Support_Booklet.pdf |
| ME | Action for ME | https://www.actionforme.org.uk/support-others/caring-for-adults-with-me/becoming-a-carer/ https://www.actionforme.org.uk/uploads/pdfs/caring-for-somebody-with-me-booklet.pdf |
| MS | MS Society | https://www.mssociety.org.uk/care-and-support/support-for-carers |
| | MS Trust | Our website has a dedicated area for care and carers. It is brief and due to be revised this year. We will be looking for input in how to make it better meet the needs of people caring for a loved one with MS. |
| MSA Trust | Multiple System Atrophy | BK050-Carers-Guide-V3.1.pdf |

| | | |
|-------------|-------------------------|---|
| Parkinson's | Parkinson's UK Scotland | https://www.parkinsons.org.uk/information-and-support/caring-someone-parkinsons |
|-------------|-------------------------|---|

Appendix D: Index of carer-specific support activities provided by neurological charities

| Name of condition | Name of charity | Detail of carer support offer |
|-------------------|----------------------------|--|
| Alzheimer's | Alzheimer Scotland | We have a 'Time for you' fund, we offer carers education, peer support, dementia cafes and counselling |
| Brain injury | Edinburgh Headway | We have a Carers Space day once a month which provides socialisation for Carers. We also treat them to holistic therapies at this and activities such as bingo etc.. We also train them on dealing with an acquired brain injury and challenging behaviour |
| Cerebral Palsy | Cerebral Palsy Scotland | We run blocks of therapy for children or adults with CP. This is obviously focussed on the person with CP. However, parents/carers play a key role and are very much part of the therapy sessions. The idea is to provide parents/carers with knowledge as to how they can support the person with CP, as well as providing that same info to the person with CP as well. These therapy sessions also often lead to a lot of discussion with the parent/carer about their emotional wellbeing. We have now started to offer psychological support to people with CP as well as their parent/carers for this reason. We have also offered some wellbeing support programmes for parents/carers (online) that are completely independent of the therapy support. |
| Epilepsy | Quarriers | We run five carer support services in Dumfries and Galloway, Glasgow, Aberdeen, Aberdeenshire, Moray |
| General | Brain and Spine Foundation | We run a peer support group for carers who look after loved ones with neurological conditions |
| MND | MND Scotland | Support Groups; Counselling; Carers Grant. |
| ME | Action for ME | https://www.actionforme.org.uk/get-support-now/help-and-support-for-you/listen-to-me-helpline/ https://www.actionforme.org.uk/get-support-now/help-and-support-for-you/information-and-support-service/ https://www.actionforme.org.uk/get-support-now/help-and-support-for-you/support-for-families/ |
| MSA | MSA Trust | We host a digital tea party for carers |
| MS | MS Trust | Our helpline is open to anyone affected by MS, including unpaid carers and family members. We often answer queries from unpaid carers on advanced care planning, respite care, supporting symptom management, mental and cognitive health and negotiating the health services. |
| Parkinson's | Parkinson's UK Scotland | Within Scotland, we provide some activities that are only open to partners, family members or friends of people with Parkinson's. These include online sessions for carers of all ages, and online sessions specifically aimed at carers of people of working age with Parkinson's. See the programme for our Autumn 2022 unpaid carers sessions here: |

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| | | <p>https://drive.google.com/file/d/12aGSzhpCkPYWpRW8v61j4wJ_nZPhw3ZL/view?usp=sharing We have 40+ local groups in Scotland, which are open to everyone affected by Parkinson's, including carers who wish to attend without the person they support and former carers. Some groups run separate subgroups specifically for carers - see eg Edinburgh Branch Carers Group: https://www.edinburghparkinsons.org/local-support/carers-support-group/ A couple of groups have also run a Side by Side course aimed at those who want to know more about supporting someone with Parkinson's. See eg here: https://www.edinburghparkinsons.org/local-support/side-by-side-with-parkinsons-course/ We offer free and confidential advice and support via local advisers based in communities across Scotland as well as our national helpline. These are open to anyone affected by Parkinson's and can be accessed by unpaid carers in their own right without the person with Parkinson's being present.</p> |
| PSP | PSPA | <p>We provide a monthly online carers support group. This is just for carers and we cover a different topic every month https://www.pspassociation.org.uk/information-and-support/for-carers/support-for-you/carers-support-group/</p> |

Appendix E: Index of questions within NAOs Members survey

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| 1.What is the name of your charity? |
| <p>2.Do you provide printed or online information for unpaid carers?</p> <ul style="list-style-type: none"> • Yes - we have specific information for unpaid carers • Yes - we have general information which is suitable for people with condition/conditions and unpaid carers • No - we target out information at people with a condition/conditions only • No - we target a different audience for our information resources • No - we do not provide information resources |
| 3.If you provide specific information for unpaid carers, please tell us about them or link them here: |
| <p>4.Do you provide specific support or activities for unpaid carers?</p> <ul style="list-style-type: none"> • Yes - we have specific support or activities for unpaid carers that are accessed independently of the person with the condition or conditions • Yes - our support and activities are open. People with a condition or conditions and unpaid carers take part together • No - our support and activities are for people with a condition or conditions. Unpaid carers only take part where the person they care for needs support to join in. • No - our support and activities are for the people with a condition or conditions and take place without an unpaid carer present • No - we do not provide support or activities |
| 5.If you provide specific support or activities for unpaid carers, please tell us about them or link to them here: |
| <p>6.If you answered no to Q1 or Q2, please tell us whether you would be interested in developing these in the future</p> <ul style="list-style-type: none"> • Yes • No • Don't know |
| <p>7.Do you currently work with carers organisations in Scotland</p> <ul style="list-style-type: none"> • Yes - we refer people to national carers' organisations for information and support • Yes - we refer people to local Carers' Centres for information and support • Yes - we have a specific project with one of more local Carers' Centres • Yes - we work with national carers' organisations on policy and rights issues • No • Don't Know |
| 8.Please tell us more about this work or provide links |
| <p>9.Do you think that the Neurological Alliance of Scotland could have a role in helping your organisation to build links with carers' organisations?</p> <ul style="list-style-type: none"> • Yes • No • Don't Know |
| 10.Do you have any ideas about how the Neurological Alliance of Scotland could do this, please tell us more here? |

Appendix F: Index of questions within Carers' Centre survey

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| 1. What is the name of your Carers' Centre? |
| 2. What services does your Carers' Centre offer? <ul style="list-style-type: none"> • Bereavement support • Carer -centred wellbeing activities (e.g., exercise, relaxation sessions) • Counselling • Emotional support • Equipment loan • Information and advice (e.g. about finance, social security, short breaks, advocacy, your rights, aids and adaptations, local care services) • Independent advocacy • Peer support • Practical training and education for carers (eg continence care, care systems, managing challenging behaviour, safer moving and assisting future care and financial planning) • Representation on local and national decision-making bodies • Signposting people to statutory organisations for support • Signposting people to neurological charities (organisations that support people with neurological conditions for support) • Short break provision • Training and education to support carers wellbeing (e.g., finding time and space for yourself, protecting your mental and physical health) • Young carers support • Other (please specify) |
| 3. In what ways do you currently work with condition-specific organisations and neurological charities (organisations supporting people with neurological conditions)? <ul style="list-style-type: none"> • We signpost to neurological charities (organisations supporting people with neurological conditions) • We signpost to condition-specific organisations but we are not aware of signposting to neurological charities (organisations supporting people with neurological conditions) • We have active collaborations or projects with condition-specific organisations • We have active collaborations or projects with neurological charities (organisations supporting people with neurological conditions) • None of the above • Other - please specify |
| 4. Which, if any, neurological charities (organisations that support people with a neurological condition) do you regularly signpost people to? |
| 5. Which, if any, neurological charities (organisations that support people living with a neurological condition) have you actively collaborated with? |
| 6. What is the primary neurological condition of the people your carers support? <ul style="list-style-type: none"> • Dementia • Neurological conditions excluding dementia • Other (please specify) |

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| <ul style="list-style-type: none"> • None of the above |
| <p>7. Do you currently provide staff or volunteers with training on important issues that can make caring for people with neurological conditions particularly challenging? (e.g communication issues, swallowing, thinking problems, mental health issues, behavioural changes, pain, physical impairments, seizures.)</p> <ul style="list-style-type: none"> • Yes - we provide specific training relating to neurological conditions • Yes - we provide general training not specific to neurological conditions • Yes – other • No – but we’d be interested in providing training like this in the future • No – and we are unable to offer this at present or in the future |
| <p>8. What services, information or support do you currently receive from neurological charities?</p> <ul style="list-style-type: none"> • Advice or support eg on social security, finance, health and social care services • Advocacy for people with neurological conditions and their carers • Condition specific training from a neurological charity/ies • Information about aids or equipment that they can loan out • Links to peer support groups • Links to information about genetic testing • Online or printed information about conditions, symptoms and treatments • Provision of support groups at your Carers’ Centre • Provision of information about a neurological condition for your Carers’ Centre to distribute • Training – about the condition and key information for carers to know • We can refer carers to neurological charities for additional support • We use resources from neurological charities to support carers at our centre • Other (please specify) • None of the above |
| <p>9. What, if any plans does your Carers’ Centre have for future collaboration with neurological charities?</p> <ul style="list-style-type: none"> • Advice or support eg on social security, finance, health and social care services • Advocacy for people with neurological conditions and their carers • Ask local neurological charities to provide support groups at your Carers’ Centre • Ask neurological charities to provide information about their condition for your Carers’ Centre to distribute • Information about aids or equipment that they can loan out • Links to peer support groups • Link to local neurological charities for the first time • Links to information about genetic testing • Online or printed information about conditions, symptoms and treatments • Receive condition specific training from a neurological charity/ies • Refer more carers to neurological charities • Training about a neurological condition and key information for carers to know • No plans to have future collaboration with neurological charities • Other (please specify) • None of the above |

10. How can we, the Neurological Alliance of Scotland (NAoS), support your aims for future collaboration with neurological charities?

- Join the NAOs as an associate member, thereby connecting with our monthly newsletter, events, campaigns and research
- NAOs to provide speakers for an event at your Carers' Centre
- Network with neurological charities local to you
- Work with NAOs on policy issues affecting Carers
- Put your Carers' Centre in touch with a specific charity
- Other (please specify)
- None of the above