

# A Quality Improvement Framework for Dementia Post-diagnostic Support in Scotland: Self-evaluation tool

Third edition

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# Introduction

The purpose of this framework is to set out what is expected from high quality dementia post-diagnostic support in Scotland. It is influenced by the outcomes that people experience because of good post-diagnostic support and the criteria that support these outcomes to be achieved. The framework is primarily for:

- practitioners delivering post-diagnostic support, and
- managers of post-diagnostic support services.

Focus on Dementia lead on the development of the framework with the support of a range of health and social care practitioners, third sector, policy, improvement and education colleagues, people with dementia, and those who care for them. This third edition acknowledges key developments since 2021 that are relevant for post-diagnostic support and care co-ordination such as:

- the new Dementia Strategy for Scotland: Everyone's Story<sup>1</sup>
- the Scottish Intercollegiate Guidelines Network (SIGN) Guideline 168: Assessment, diagnosis, care and support for people with dementia and their carers<sup>2</sup>
- Brain Health Scotland's mission on brain health<sup>3</sup>
- the principles of Getting it Right for Everyone (GIRFE)<sup>4</sup>, and
- My Health, My Care, My Home<sup>5</sup>.

Focus on Dementia is the national improvement programme for dementia in Scotland, based within Healthcare Improvement Scotland. We work in partnership with national organisations, health and social care partnerships, people with dementia, and those who care for them to improve the quality of care and support. Our work supports the implementation of the Dementia SIGN Guideline 168 with a focus on:

- post-diagnostic support and integrated care co-ordination in the community, and
- reducing stress and distress for people with dementia in hospital and care homes.

Focus on Dementia also facilitate the national Post-diagnostic Support Leads Network that meets quarterly, and a wider dementia practitioner network, to support learning and improvement for all practitioners delivering dementia support in Scotland. Contact [his.focusondementia@nhs.scot](mailto:his.focusondementia@nhs.scot) to find out more about our networks and network membership from local areas.

# Background to improving post-diagnostic support for people with dementia in Scotland

In 2011, Alzheimer Scotland launched the 5 Pillar model of post-diagnostic support<sup>6</sup>. The purpose of post-diagnostic support is to equip people living with dementia, and those who care for them, with the tools, connections, resources and plans they need to live as well as possible and prepare for the future. Informed by Alzheimer Scotland's 5 Pillars model of post-diagnostic support, Scotland's second National Dementia Strategy<sup>7</sup> set out the target that all people newly diagnosed with dementia will be offered post-diagnostic support.

Dementia in Scotland: Everyone's Story, our current dementia strategy<sup>1</sup>, continues to emphasise the importance of prioritising the development of post-diagnostic support in Scotland and maximising its reach and impact. The local delivery plan standard<sup>8</sup> continues to state that *everyone newly diagnosed with dementia will be offered a minimum of one year's post-diagnostic support, coordinated by an appropriately trained Link Worker, including the building of a person-centred support plan*. Performance against the standard is reported in two parts:

1. The percentage of people estimated to be newly diagnosed with dementia who were referred for post-diagnostic support.
2. The percentage of people referred who received a minimum of one year's support coordinated by a link worker, including the building of a person-centred support plan.

## Why do we need this framework?

While statistical data on post-diagnostic support is collected, there has been no national mechanism for assuring the quality of the support people are receiving. We know from speaking to people with dementia, those who care for them, practitioners and other professionals, that approaches to post-diagnostic support and the quality of post-diagnostic support services vary throughout the country.

This framework therefore aims to set out what is necessary for high quality post-diagnostic support and the policies, principles, rights and standards that underpin service provision (see [Appendix 3](#)). By using the principles of personalisation and personal outcomes, the framework is relevant for post-diagnostic support practitioners working with people across the 5 Pillars model and accounts for situations where people are not diagnosed at an early stage of their dementia but are still eligible for, and offered, post-diagnostic support whilst requiring more care co-ordination as described by Alzheimer Scotland's 8 Pillars model<sup>9</sup>. There are references throughout the framework and guidance to acknowledge this.

The words 'post-diagnostic support practitioners' are used throughout the framework to cover dementia link workers and all other staff who deliver post-diagnostic support as the named practitioner. Unpaid carers, care partners and families are covered by 'those who care for' the person.

## Key enablers to high quality post-diagnostic support

The framework is influenced by four key areas which are essential for the delivery of high-quality post-diagnostic support (see Figure 1).

**Figure 1: The key areas of post-diagnostic support**

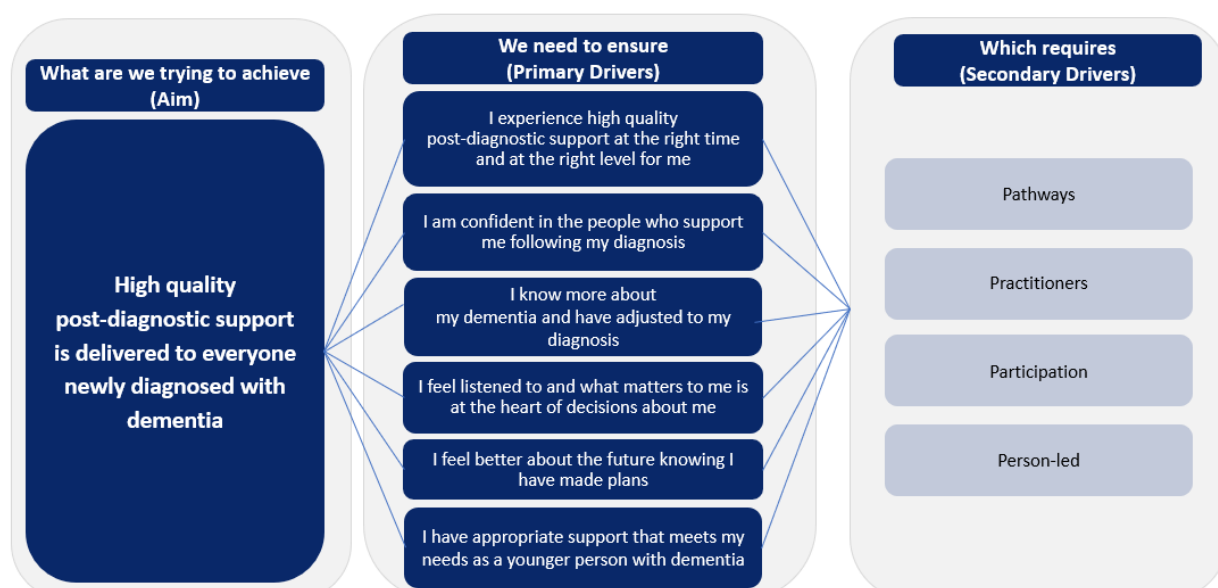


A clear business case will sustain the delivery of post-diagnostic support and create conditions for the service to flourish. The necessary resources, leadership support, mainstream funding and clear commissioning intentions based on robust local data will support high quality provision. Measurement to demonstrate the benefits of post-diagnostic support and, in turn, the economic benefit to organisations, supported by case studies reflecting the real-life experience of post-diagnostic support, will assist the business case.

The driver diagram in Figure 2 below illustrates the overall aim of the framework and the main factors that contribute to achieving the aim:

- the primary drivers are the personal outcomes people can experience from receiving high quality post-diagnostic support
- the secondary drivers are the four key areas in figure 1 that underpin the outcomes, and
- the change ideas are the quality criteria – the practical things that need to be in place to meet the aim.

**Figure 2: Driver diagram for high quality post-diagnostic support**



## Why is it important to use the framework?

The framework is recognised in the SIGN Guideline 168 and the dementia strategy for Scotland as a quality measure for universal adoption across post-diagnostic support services in Scotland. It aims to ensure everyone is working towards the same standard of delivery for people in each local area. It can also be used to support the commissioning process and to help monitor service delivery.

Having a common framework creates shared aspirations and understanding, uniting the post-diagnostic support community where learning and best practice can be shared.

Benefits of using the framework include:

- to help design the post-diagnostic support service
- to explore and evidence how well the post-diagnostic support service is supporting positive outcomes for people with dementia and those who care for them
- to improve the experience of practitioners delivering post-diagnostic support
- to improve local decision-making to ensure staff have the necessary skills and resources to deliver high quality post-diagnostic support
- to act as a motivator for service improvement
- to provide a quality assurance system for post-diagnostic support, for example, commissioners or senior leaders may ask for reports on how the service is performing
- to provide quality assurance evidence for any external scrutiny bodies such as the Care Inspectorate
- to inform national policy, education and improvement programme priorities, and
- to ensure that services are delivered to a consistently high standard.

Have a look at the [short animation and case studies](#) to learn how others have used it.

## How to use the framework

The framework is primarily a self-assessment tool to help service managers and post-diagnostic support practitioners to consider:

- where their service meets the criteria
- where certain aspects could be improved, and
- where a clearer business case is necessary to ensure the service has the appropriate resources to operate as described by the framework.

It is not a questionnaire to be used with people with dementia and those who care for them. The service will have separate methods for gathering such feedback.

The framework is influenced by personal outcomes the person with dementia and those who care for them can experience because of high quality post-diagnostic support. As such, each section of the framework is headed by a personal outcome written in the first person and a set of quality criteria for service provision has been assigned to each outcome. There is a scoring column against each criterion to rate current practice on a scale from 1-6 and a section for briefly recording the source of evidence and/or any comments. Post-diagnostic support practitioners should reflect on each of the criteria and attribute a score on how well they believe their service meets the criterion. The scoring options are as follows.

1. Unsatisfactory: urgent remedial action required
2. Weak: priority action required
3. Adequate: strengths just outweigh weaknesses
4. Good: important strengths, with some areas for improvement
5. Very Good: major strengths
6. Excellent: outstanding or sector leading

The quality criteria apply to people with dementia, however there is a specific section with additional criteria for supporting people with young onset dementia.

The guidance in [Appendix 1](#) suggests how each criterion could be evidenced. It is anticipated that a post-diagnostic support service improvement plan can be drawn up for the areas that a service wishes to improve on, and this can be further organised into the top three priorities for improvement (see [Appendix 2](#) for an example improvement plan template).

The use of the framework is optional, and the frequency and method of using the framework can be locally determined. It is recommended it be used:

- as a guide when setting up a new service
- at least annually as a self-assessment, and more frequently if required, to identify improvement priorities to inform practice change
- to audit or peer audit existing services to inform service improvement
- as a team exercise, and



- by individual practitioners who wish to self-assess their practice against relevant criteria which, in turn, can inform discussions at personal development reviews.

Services and practitioners can choose to focus on a section or two or a few chosen criteria at a time. The whole framework does not have to be gone through in one session, its use can be planned throughout a year.

## Next steps

The framework is available for all post-diagnostic services and practitioners to use.

You are welcome to feedback on any aspect of the framework to the Focus on Dementia team. We gather all feedback to support future editions of the framework and take any developments into account with respect to the implementation of the dementia strategy for Scotland.

A 'companion' resource called '[Making the most of your post-diagnostic support](#)', is also available for people with dementia and carers. It was produced in collaboration with Alzheimer Scotland, the Scottish Dementia Working Group and the National Dementia Carers Action Network. Hard copies can be ordered from [info@alzscot.org](mailto:info@alzscot.org). This resource explains to people newly diagnosed with dementia that they are entitled to post-diagnostic support, explains what a good service looks like and helps them to plan their support.

If you have any comments or queries, you can contact the Focus on Dementia team, Healthcare Improvement Scotland at [his.focusondementia@nhs.scot](mailto:his.focusondementia@nhs.scot).

# The Post-diagnostic Support Quality Improvement Framework

See [Appendix 1](#) for guidance and suggested sources of evidence for each of the quality criteria.

| <b>1. I experience high quality post-diagnostic support at the right time and at the right level for me</b>   |                 |                          |
|---|-----------------|--------------------------|
| <b>Quality criteria for the service (how to support the above outcome)</b>  | <b>Rate 1-6</b> | <b>Evidence/comments</b> |
| a) Post-diagnostic support is offered, planned and delivered at a pace that reflects the person's needs and priorities.   |                 |                          |
| b) Individuals and those who care for them are asked how they would prefer to connect with the service, for example to meet in person and be visited at home, to use a digital platform or to have a blend of both. |                 |                          |
| c) The service has approved arrangements in place for using technology to connect with individuals and follows best practice principles when using virtual methods.   |                 |                          |
| d) There is equitable access to the service.  |                 |                          |
| e) The service can provide support that is culturally sensitive.  |                 |                          |
| f) Information about the service is provided in a language and format that is easy to understand.   |                 |                          |

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| g) The service can also support individuals who are not diagnosed at an early stage of their dementia by ensuring they have a named practitioner. This can be delivered by a PDS practitioner or may be more appropriately delivered by a member of the multi-disciplinary team where the needs are more advanced or complex. |  |  |
| h) The service can recognise the need for urgent post-diagnostic support, for example where the dementia is rapidly progressive, and has clear criteria for prioritising/fast tracking appropriate referrals.   |  |  |
| i) The service works closely with others to ensure the person's care and support is well co-ordinated and delivered by the right people for the stage of their dementia and the needs that they have.   |  |  |
| j) The service has approved arrangements in place for sharing personal information appropriately.   |  |  |
| k) The person and those who care for them are clearly informed of different agencies that can support them and have provided appropriate consent to be referred to these.   |  |  |
| l) The post-diagnostic support practitioner has a clear understanding of the roles of other professionals and can refer and support access to these.  |  |  |
| m) Clear communication and support are provided to empower the person to plan their post-diagnostic support, self-manage their condition where possible, prepare for the future and, where  |  |  |

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| applicable, prepare for being discharged from post-diagnostic support.  |  |  |
| n) The post-diagnostic support practitioner records the person's status when post-diagnostic support ends, for example if the person is self-managing or has been referred to another service.  |  |  |
| o) The person and those who care for them are given contact information so that they know how to seek support when their post-diagnostic support ends, or how to access the service should they initially decline support or leave the service early. |  |  |
| p) The service considers how to manage waiting lists or demand for post-diagnostic support, for example, through group sessions or establishing ways of supporting people while they wait (see <a href="#">Appendix 1</a> guidance for example).      |  |  |

| <b>2. I am confident in the people who support me following my diagnosis</b>  |                 |                          |
|---|-----------------|--------------------------|
| <b>Quality criteria for the service (how to support the above outcome)</b>  | <b>Rate 1-6</b> | <b>Evidence/comments</b> |
| <b>The practitioner delivering post-diagnostic support:</b>   |                 |                          |
| a) Has a clear remit and dedicated time and resources to carry out their role.  |                 |                          |
| b) Has good communication skills and the ability to build trust and develop strong relationships based on what matters to the person and those who care for them. |                 |                          |

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| c) Has the key knowledge and skills to support the person and those who care for them as outlined in the Promoting Excellence resources <sup>10, 11</sup> (see link in <a href="#">Appendix 3</a> ). This includes the ability to engage with the person via technology if the person chooses this as a preferred method.   |  |  |
| d) Is reliable, proactive and creative, providing consistent support at a pace that reflects the person's post-diagnostic support needs.  |  |  |
| e) Actively involves and seeks feedback from the person and those who care for them on the experience of post-diagnostic support, what's gone well and what could be improved. This includes being part of a national initiative to use a Single Quality Question <sup>12</sup> to help capture an overall measure of the difference post-diagnostic support makes (see link in <a href="#">Appendix 3</a> ). |  |  |
| f) Supports the person to keep in touch with contacts who can provide support.  |  |  |
| g) Informs the person and those who care for them about available activities, local opportunities and online resources and, where required, supports access to these.   |  |  |
| h) Can suggest strategies to help the person remain independent for as long as possible, such as small adaptations to the person's home environment, and can refer on to other professionals, such as occupational therapy, if more complex environmental changes are required.   |  |  |

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| i) Can access and provide advice on driving to ensure the legal obligations with regards to driving and dementia are understood and fulfilled. Can also help with advice on assisted travel options.  |  |  |
| j) Can provide information about accessing and using technology to connect with others and on assistive technology to promote independence for as long as possible.   |  |  |
| k) Receives regular support and supervision which allows for reflection on personal outcomes-focused approaches and supervision of caseload.  |  |  |
| l) Has access to peer support networks, post-diagnostic support resources and appropriate administrative support to keep administrative tasks to a minimum.   |  |  |
| m) Liaises with relevant health and social care and housing services in their catchment area to ensure they know about the post-diagnostic support service, how to make referrals, and if someone they are supporting is receiving post-diagnostic support. |  |  |
| n) Understands the national commitment <sup>13</sup> to post-diagnostic support and how their role contributes to meeting the commitment <sup>8</sup> .   |  |  |

| <b>3. I know more about my dementia and have adjusted to my diagnosis</b>  |                 |                          |
|--|-----------------|--------------------------|
| <b>Quality criteria for the service (how to support the above outcome)</b>   | <b>Rate 1-6</b> | <b>Evidence/comments</b> |
| a) The post-diagnostic support practitioner has, or can access, the necessary knowledge to be able to provide the person and those |                 |                          |

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| who care for them with information on the type of dementia that affects them.   |  |  |
| b) Support is provided to enable the person to develop strategies to manage, and adapt to, living with their particular type of dementia and to manage risks, for example, strategies for going out safely and using the Herbert Protocol <sup>14</sup> . |  |  |
| c) Support is provided to enable the person to attend to physical health needs where appropriate.   |  |  |
| d) Those who care for the person are supported to develop strategies to manage, and adapt to, caring for the person with dementia and to maximise and complement existing strengths.  |  |  |
| e) The person and their carer have access to peer support.  |  |  |

| <b>4. I feel listened to and what matters to me is at the heart of decisions about me</b>  |                 |                          |
|--|-----------------|--------------------------|
| <b>Quality criteria for the service (how to support the above outcome)</b>   | <b>Rate 1-6</b> | <b>Evidence/comments</b> |
| a) The person agrees to being referred for post-diagnostic support, is fully involved in identifying and agreeing what kind of support they need and in follow-up and monitoring.  |                 |                          |
| b) Where the person chooses not to engage with the service, this right is respected if concerted efforts to encourage take up of support prove unsuccessful. Consideration should still be given to how carer support can be provided or accessed. |                 |                          |

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| c) What is important to the person and those who care for them, and any other information used to support decision-making, is clearly recorded and shared appropriately.                               |  |  |
| d) The person is empowered and enabled to make the most of their strengths and achieve what matters to them.   |  |  |
| e) The person is supported to continue to be included in their community.  |  |  |
| f) The person is supported to maintain doing activities that are important to them.  |  |  |
| g) The person is enabled to communicate in a way that is right for them. The post-diagnostic support practitioner can access advice on the different approaches that may support the person with this. |  |  |
| h) Those who care for the person are listened to and supported in their caring role.   |  |  |

| <b>5. I feel better about the future knowing I have made plans</b>  |                 |                          |
|---|-----------------|--------------------------|
| <b>Quality criteria for the service (how to support the above outcome)</b>  | <b>Rate 1-6</b> | <b>Evidence/comments</b> |
| a) The post-diagnostic support practitioner is equipped to empower and support the person and those who care for them to discuss and make plans for the future. |                 |                          |
| b) The person is supported at the earliest opportunity to develop a personal plan which reflects what matters most to them and clearly details their wishes.    |                 |                          |



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| c) The person and those who care for them are supported to make practical arrangements, for example claiming benefits they are entitled to, accessing self-directed support and making a will. |  |  |
| d) The person and those who care for them are supported to set up Power of Attorney arrangements.  |  |  |
| e) The person and those who care for them are supported to find out how to participate in research if this is something they wish to do.   |  |  |
| f) With the person's permission, the post-diagnostic support practitioner shares relevant information with the person's GP to inform their Key Information Summary (KIS) <sup>15</sup> .       |  |  |

Please note that Outcomes 1-5 and associated criteria should be followed for supporting people living with young onset dementia. Outcome 6 contains additional criteria essential for supporting people with young onset dementia.

| <b>6. I have support that meets my needs as a younger person with dementia</b>  |                 |                          |
|---|-----------------|--------------------------|
| <b>Quality criteria for the service (how to support the above outcome)</b>  | <b>Rate 1-6</b> | <b>Evidence/comments</b> |
| a) The service has good connections with neurology, memory clinics and Adult Mental Health teams to enable seamless referral to post-diagnostic support following diagnosis.  |                 |                          |
| b) The service can appropriately prioritise young onset referrals and provide rapid support due to the risk of faster deterioration in young onset dementia and the potential for greater complexity of presentation and circumstances. |                 |                          |

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| c) The post-diagnostic support practitioner knows how to access information on rare dementias and specialised young onset information and support including peer support.   |  |  |
| d) The person is supported to access age-appropriate services and meaningful opportunities.   |  |  |
| e) The post-diagnostic support practitioner is aware of the issues relating to parents, children and young carers of people with young onset dementia, can access age-appropriate information and support and liaise closely with other agencies to ensure the support is co-ordinated for the whole family.  |  |  |
| f) The person has support to communicate with employers about their diagnosis so that reasonable adjustments can be made to be able to continue working where possible.   |  |  |
| g) The person and those who care for them are supported to work through any financial complexities arising from e.g. giving up employment, managing mortgage payments etc. and to make practical arrangements, for example claiming benefits they are entitled to, accessing self-directed support, making a will and setting up Power of Attorney. |  |  |
| h) The post-diagnostic support practitioner is aware that a major barrier to accessing support among people with young-onset dementia is denial, refusal to seek help and fear of stigma, and can work with the person to overcome this.  |  |  |

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| i) The post-diagnostic support practitioner is aware that people with young-onset dementia can experience poor mental health, with increased anxiety, depression and thoughts of suicide, and can recognise the signs and seek appropriate support.  |  |  |
| j) The post-diagnostic support practitioner is aware of the support the person's family might need, where the person themselves is having challenges, they will also be experienced by family and other people close to them.  |  |  |
| k) The post-diagnostic support practitioner recognises and is sensitive to the challenges that may arise from the person losing skills at a younger age and potentially faster pace, whilst ensuring that risks are appropriately managed, for example in relation to driving, employment and family dynamics. |  |  |
| l) The service should ensure that the post-diagnostic support practitioner for people with young onset dementia has multi-disciplinary team support and receives regular support and supervision, including emotional support, to cope with complex situations.  |  |  |

# Appendix 1: Guidance on suggested sources of evidence for the quality criteria

| 1. I experience high quality post-diagnostic support at the right time and at the right level for me |   |
|--|---|
| Quality criteria   | Suggested evidence  |
| a)   | <p>The support begins with an outcomes-focused conversation on what is most important to the person, taking care to recognise and address any initial need for emotional support, and how much input they would like and when they require the support. Key aspects of this conversation should be captured somewhere in the person's file, for example in a support-planning document or continuation notes. See <a href="#">Appendix 3</a> for resources to learn more about personal outcomes and outcomes-focused conversations.</p> <p>Feedback from individuals on their experience of post-diagnostic support.</p> |
| b)   | <p>Support-planning assessments identify and record information on how the person and those who care for them prefer to connect with the service and what support they might need with respect to their chosen method. This is particularly important where the person might need their carer present at appointments to offer support.</p>   |
| c)   | <p>The service can demonstrate that it has considered and approved arrangements for using technology to connect with individuals and follows best practice principles when using such methods. This could include having a Standard Operating Procedure in relation to supporting people virtually, having training sessions for staff on principles of best practice and being able to evidence a person-led approach when using technology. The RNIB <a href="#">Good practice guidelines for using technology to support people with sight loss and dementia</a> contain useful general points.</p>                    |
| d)   | <p>The service can demonstrate that it does not discriminate against anyone within their catchment area who could benefit from accessing post-diagnostic support. This might be evidenced through:</p> <ul style="list-style-type: none"> <li>• equality and diversity training for staff</li> <li>• carrying out an Equality Impact Assessment of the service</li> <li>• liaison with care homes to deliver PDS</li> <li>• supporting people to access and use technology such as helping with Near Me practice tests.</li> </ul>  |

|    |  |
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| e) | <p>The service can demonstrate that it can deliver culturally sensitive post-diagnostic support. Culturally sensitive means being aware and respectful of cultural differences and practices of individual from diverse backgrounds. This might be evidenced through:</p> <ul style="list-style-type: none"> <li>• equality and diversity training for staff</li> <li>• carrying out an Equality Impact Assessment of the service</li> <li>• team reflection on diversity and cultural sensitivity</li> <li>• team awareness of increased stigma among minority ethnic populations</li> <li>• recording of protected characteristics; accessing specific resources such as the <a href="#">Lesbian, gay, bisexual and transgender (LGBT) and dementia toolkit</a>, and</li> <li>• accessing translation services and producing anonymised case studies</li> <li>• Personal planning.</li> </ul> <p>Note: The Public Health Scotland PDS dataset includes recording of equality data.</p> |
| f) | <p>The service leaflet/information meets best practice guidance for written literature for people with dementia, for example see the <a href="#">DEEP Guide - Writing dementia-friendly information</a>.</p> <p>Evidence of involvement of people with dementia and those who care for them in the development of information, for example records of meeting attendance, feedback on drafts, and focus groups.</p> <p>Feedback from individuals on how accessible the PDS service information is.</p>   |
| g) | <p>Where the person has been assessed as having needs that are more advanced or complex, the service should still ensure the person is allocated a named worker as they are entitled to PDS. Where the PDS role may be more appropriately met by a different member of the multi-disciplinary team or by a different service, date of referral to this service is documented. Date of referral to this service is documented and all information as per the LDP Standard requirements is collected for the PHS return.</p>   |
| h) | <p>Once a person has been referred to the PDS service and it is apparent that they need urgent input, for example has a rapidly deteriorating dementia or is in a high risk situation that the service could mitigate with quick intervention, then the service can demonstrate that it has the ability to triage and prioritise referrals rather than operate a standard 'first come first served' waiting list.</p>  |
| i) | <p>The service considers how well the person's care and support is co-ordinated and explores options for good care co-ordination. See the <a href="#">Twelve Critical Success Factors for Care Co-ordination self-assessment tool</a>.</p>   |
| j) | <p>The service adheres to strict information governance protocols; data protection is included in policy and procedures and covered in staff training.</p>   |

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| k) | The service seeks and records appropriate consent from the person with dementia and those who care for them to share information with other agencies who can help.  |
| l) | <p>The PDS practitioner knows about other professionals who can support the person and how to refer to such services. This covers a wide-range of professionals, key ones being Allied Health Professionals (AHPs) such as Occupational Therapists, Speech and Language Therapists, Dietitians, Physiotherapists and Podiatrists (see Connecting People Connecting Support framework, Connecting you to Support in <a href="#">Appendix 3</a> for further information. Also see AHP led self-management resources at <a href="http://www.alzscot.org/ahpresources">www.alzscot.org/ahpresources</a>).</p> <p>Other important services include Social Workers, Community Psychiatric Nurses, Welfare Rights Advisors, Dementia Advisors, Dementia Resource Centres, Meeting Centres Scotland, Carer Centres and Carer Support Workers.</p>   |
| m) | <p>The PDS practitioner can articulate the benefits of accepting PDS to the person and those who care for them and tailor their approach to the individual. Evidence of this may include the use of the 'Making the most of your post-diagnostic support' booklet. Order free copies from <a href="mailto:info@alzscot.org">info@alzscot.org</a>. You can also read this <a href="#">case study</a> on its use.</p> <p>The PDS practitioner is confident in broaching the subject of future planning, encouraging people to think about what is important and making a note of this.</p> <p>If the person's dementia is diagnosed at a later stage, the ability to self-manage may have diminished therefore alternative approaches should be used such as making use of carer/family input and exploring the person's known past wishes to assist with future planning. This could be evidenced in support planning and personal planning documents/tools.</p> |
| n) | If the person leaves the service, the reason is recorded in their file and in Public Health Scotland data reporting.  |
| o) | The person should be given written information on contact details for the service so that they can get back in touch should they need it.   |
| p) | Waiting lists should be regularly reviewed. An example of proactively managing a waiting list is running a drop-in support group for people who are yet to be allocated a named practitioner. This model can begin to address some of the elements of PDS including access to peer support. Contact <a href="mailto:his.focusondementia@nhs.scot">his.focusondementia@nhs.scot</a> to find out more about good practice examples.   |

| <b>2. I am confident in the people who support me following my diagnosis</b> |  |
|--|--|
| <b>Quality criteria</b>  | <b>Suggested evidence</b>  |
| a)   | The PDS practitioner has a job description that describes and incorporates their PDS role. They can clearly describe their role and any issues with remit and time are raised and addressed through support and supervision sessions and actions from these are recorded.  |
| b)   | <p>The PDS practitioner knows how to conduct an outcomes-focused conversation with individuals to determine what matters to them. Evidence of this can include completion of the <a href="#">Getting To Know Me document</a>, personal planning documentation and feedback from people with dementia and those who care for them.</p> <p>Relationship-building and listening to all involved is also an integral part of 8 Pillars support<sup>6</sup>. Where the person is not in the early stages of their dementia, evidence could include use of reminiscence and other approaches to help determine important information about the personal thoughts and wishes of the person - making a connection with someone through their past can help with present and future planning.</p> |
| c)   | <p>The PDS practitioner is trained to Enhanced Level of the Promoting Excellence Framework or as a minimum to Skilled Level and has a development plan that addresses any skills and knowledge that need to be attained to meet Enhanced Level. This includes being <a href="#">Trauma informed</a>.</p> <p>The PDS practitioner is confident in using, or is supported to use and has access to, technology such as Attend Anywhere (Near Me), Zoom and Microsoft Teams.</p> <p>There may also be evidence that the team know about, and have worked through, the NES and Scottish Social Services Council resource <a href="#">Promoting Excellence in Supporting People Through a Diagnosis of Dementia</a>.</p> <p>Feedback from individuals on their experience of PDS.</p>         |
| d)   | <p>The PDS practitioner has a clear plan and structure of supporting the person, and the person's preferred pace, method and level of support is documented. The support is not ad hoc unless the person has clearly requested that they would prefer ad hoc contact; this preference is recorded.</p> <p>Reliability, proactivity and creativity can be evidenced through personal planning and feedback from individuals.</p>  |
| e)   | The service routinely involves and seeks feedback from individuals on how the PDS service is making a difference and what could be better. This may be done by questionnaire, focus groups, other feedback methods such as Emotional   |

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|    | <p>Touchpoints or Talking Mats and writing up case studies. The request for feedback should include asking the person and those who care for them if they have felt listened to. The service should embed the <a href="#">Single Quality Question</a> for PDS into its evaluation methods to support the local and national picture of the quality of PDS.</p> <p>People living with dementia should be involved in service design and developments. See 'Participation resources' in <a href="#">Appendix 3</a>.</p>  |
| f) | <p>Personal planning identifies natural networks and any strategies in place to establish and maintain contacts, including the use of the connecting virtually online. For those with more progressed dementia, records may show reliance on others to maintain contacts with them to ensure support is offered.</p>   |
| g) | <p>The PDS practitioner knows or finds out about the person's local community resources and explores further afield for opportunities and activities that are relevant for what matters to the person. This could be evidenced in personal planning documentation and feedback from individuals on their experience of PDS.</p>  |
| h) | <p>The PDS practitioner understands practical interventions that can make a difference in the home environment such as Cognitive Stimulation Therapy and Occupational Therapy Home Based Memory Rehabilitation, local Care and Repair Services, access to the internet and IT equipment to connect with services and others and supports the person to access these where available.</p> <p>The Dementia Services Development Centre's (DSDC) <a href="#">Environments for Ageing and Dementia Design Assessment Tool (EADDAT), Tier 1</a> is an extremely useful resource for assessing the person's home environment for simple adaptations.</p> <p>DDAT tool are useful resources for looking at the home environment.</p> <p>Feedback from individuals on their experience of PDS.</p> |
| i) | <p>The PDS practitioner can readily supply the person and those who care for them with advice on driving and dementia to ensure they understand the legal obligations and can feedback any concerns to the multi-disciplinary team, for example if advice is not being followed.</p> <p>Useful information, especially the law on driving and dementia, can be found on the <a href="#">Alzheimer's Society</a> and <a href="#">Dementia UK</a> webpages. For information on how to access a driving assessment in Scotland, and to understand what the assessment entails, look at the <a href="#">Scottish Driving Assessment Centre (SDAS)</a> webpages.</p> <p>Additional resources to improve PDS practitioner knowledge of driving and dementia:</p>                                 |



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|    | <p>Alzheimer Scotland AHP blog: <a href="#">Driving and Dementia?   Let's Talk about Dementia</a></p> <p>The PDS practitioner can help to search for local assisted travel options such as Dial-a-Ride, <a href="#">MyBus</a> and Community Transport. Also see Alzheimer Scotland's <a href="#">Helpcard</a> and the <a href="#">Thistle Assistance Programme</a> which can help with travelling safely.</p> <p>General links:</p> <ul style="list-style-type: none"> <li>• <a href="#">National Entitlement Card</a></li> <li>• Scotrail <a href="http://www.scotrail.co.uk/form/assisted-travel">www.scotrail.co.uk/form/assisted-travel</a></li> <li>• First <a href="https://www.firstbus.co.uk/bus-accessibility">https://www.firstbus.co.uk/bus-accessibility</a></li> </ul>  |
| j) | <p>The PDS practitioner is confident in using technology such as <a href="#">Near Me</a> to connect virtually with people and can access support to enable them to do so. The practitioner is also aware of:</p> <ul style="list-style-type: none"> <li>• The <a href="#">Living well with dementia - for everyone</a> – app for self-management.</li> <li>• ADAM (About Digital and Me) <a href="http://www.meetadam.org">www.meetadam.org</a>. Helping people to find technology products matched to their needs. Based on unbiased, trusted recommendations from people with lived experience of long-term conditions. This is a free service developed by Alzheimer Scotland with funding from Scottish Government.</li> <li>• The <a href="#">Virtual Resource Centre</a> (VRC) is an online space which provides people access to groups, activities, and information sessions all from the comfort of their own homes. It is housed on the Alzheimer Scotland website. People can access a range of free live and 'on demand' activities including live music sing-alongs, arts and crafts, quizzes, seated exercises, and relaxation techniques. The VRC also runs a program of information sessions on topics such as financial advice, using technology, and assistive technology and <a href="#">Dementia Circle recommended products</a>.</li> </ul> <p>Training records may show attendance at assistive technology sessions. Contact Alzheimer Scotland for advice on digital solutions <a href="mailto:digital@alzscot.org">digital@alzscot.org</a>.</p> <p>Personal planning documentation records the person's consent to present or future use of technology, such as wearing a tracking device to keep safe, and any support required to use this.</p> <p>Feedback from individuals on their experience of PDS.</p> |
| k) | <p>Support and supervision format allows for reflection on personal outcomes-focused approaches and includes caseload supervision.</p> <p>Support and supervision records and dates.</p>   |

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| l) | <p>The PDS practitioner attends team meetings, PDS practitioner network events, is a member of Focus on Dementia's practitioner network and receives the newsletter.</p> <p>There is a reasonable level of administrative support to assist the PDS practitioner.</p>  |
| m) | <p>The PDS practitioner informs other health and social care and housing providers in their area, who support people with dementia, of the existence of PDS and the service that can be provided. Consider, for example, if GP practices have been informed that the service is available, give them information leaflets and a key contact. With the person's permission, inform services who support the person of any PDS input. It is important to know that housing providers have a <a href="#">Housing and Dementia Practice Framework</a> similar to this PDS framework. The housing framework includes criteria on PDS.</p> |
| n) | <p>The PDS practitioner understands Scotland's national dementia strategy, the SIGN Dementia guideline (see <a href="#">this SIGN booklet</a> for people with dementia and carers for the easy-read version) and the national commitment to delivering and improving post-diagnostic support and how their role fits with this. This could be asked as a question at interview, discussed at team meetings, at support and supervision, and at personal development reviews.</p>   |

### 3. I know more about my dementia and have adjusted to my diagnosis

| Quality criteria | Suggested evidence   |
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| a)               | <p>The PDS practitioner has undertaken education on the different types of dementia and knows where to find information and support for rarer types of dementia e.g. linking with <a href="#">Rare Dementia Support</a>. This could be evidenced through personal development plans, personal planning and feedback from individuals on their experience of PDS.</p>   |
| b)               | <p>Personal planning documentation records coping strategies. If self-management is no longer viable for the person, then evidence may be about the support others receive to support the person with the changes taking place.</p> <p>The PDS practitioner can either carry out or access risk assessments. Personal planning documentation records strategies for keeping as safe as possible for example planning ahead with the use of the <a href="#">Herbert Protocol</a> if the person is, or could become, vulnerable to going missing, and considering other safety options such as using GPS. See Alzheimer Scotland <a href="#">guidance on getting out and about safely</a>.</p> |

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|    | Feedback from individuals on how the PDS service is making a difference to coping abilities.  |
| c) | <p>Personal planning should pay attention to any support the person needs for their physical health and wellbeing.</p> <p>The following are just a few examples of where the PDS practitioner can support physical health and can signpost appropriately:</p> <p>Supporting the person to see their GP if necessary.</p> <p>Understanding that <a href="#">delirium</a> is much more common in older people, especially people with dementia.</p> <p>Research shows that cognitive impairment significantly lowers the odds of sight checks and dentist visits<sup>16</sup>.</p> <p>Oral health - an early dental assessment allows for forward treatment planning and prevention of future dental problems. It is helpful to have discussions about future dental treatment need before capacity and consent, as well as potential distress for the person, become issues. PDS practitioners should encourage people newly diagnosed with dementia to make an appointment with their dentist, to start these discussions and pre-empt dental problems from arising.</p> <p>In relation to oral and dental health, PDS practitioners should read Alzheimer Scotland's <a href="#">Oral Health and dementia</a> information sheet. Information on day-to-day oral care is provided by <a href="#">Caring for Smiles</a>, Scotland's national oral health promotion, training and support programme, which aims to improve the oral health of older people and <a href="#">Open Wide</a> which aims to improve the oral health of adults with additional care needs. PDS practitioners should consider undertaking training in oral health. This can be delivered to health and social care staff by contacting <a href="#">Caring for Smiles Coordinators</a> or, for those under 65 years old, <a href="#">Open Wide Coordinators</a> in Health Boards across Scotland. <a href="#">Accredited Caring for Smiles training</a> is also offered.</p> <p>Eye health – where appropriate to the person, supporting them to arrange and attend eye appointments including eye tests, wearing prescription spectacles, keeping spectacles clean.</p> <p>Hearing – where appropriate to the person, supporting them to arrange and attend hearing appointments, including hearing tests, wearing hearing aids, keeping hearing aids in working order.</p> <p>Frailty - PDS practitioners are aware of the common signs and symptoms of frailty (<a href="#">see Ageing and Frailty Standards</a>) and can identify where effective prevention and early support may reduce the person's risk of developing frailty. Healthcare</p> |

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|    | <p>Improvement Scotland's <a href="#">Focus on Frailty</a> webpages contain useful information and resources on frailty.</p> <p>Staying active – supporting the person to stay active and mobile. If the person has gait problems, then early physiotherapy intervention is very important. Physiotherapy can help if the person is having difficulty walking and being active or having falls.</p> <p>Eating well – referring to a dietitian if the person is having significant problems with nutrition. See Dementia UK's leaflet <a href="#">Eating and Drinking</a> for tips.</p> <p>Foot health - <a href="#">The CPR for feet</a> campaign highlights the importance of checking feet, protecting at risk feet and referring to appropriate health care professionals if an active problem is detected. Alzheimer Scotland's <a href="#">Footcare at Home</a> gives specific guidance for dementia.</p> <p>Medications management – support to manage and take medication where appropriate and to have medications reviewed especially where <a href="#">polypharmacy</a> may be an issue.</p> <p>Brain Health - Evidence that PDS practitioners are aware of Brain Health Scotland's mission and the key messages on brain health. The service holds <a href="#">Brain Health Scotland</a> leaflets.</p> <p>Support planning and feedback from individuals can evidence how the PDS service is making a difference to physical health.</p> |
| d) | <p>Support planning may include information on carer education, carer support groups, carer centres, information given to carers about dementia and coping strategies.</p> <p>Feedback from those who care for the person on how the PDS service is making a difference.</p>  |
| e) | <p>Support planning can evidence offers and take up of peer support opportunities.</p> <p>For people who require support at the '8 Pillars level'<sup>9</sup>, the person may be attending a group setting, such as a day services, dementia cafe or meeting centre, which can be a source of peer support.</p> <p>If the person is housebound then their ability to access peer support may be limited, however the service may be able to evidence use of creative methods such as technology to help people connect with others.</p> <p>Feedback from individuals on how the PDS service is supporting them to meet others.</p>  |

| <b>4. I feel listened to and what matters to me is at the heart of decisions about me</b> |   |
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| <b>Quality criteria</b>   | <b>Suggested evidence</b>   |
| a)  | <p>Assessment, support planning and review notes clearly evidence that the person has agreed to the referral and has been involved in decision-making throughout.</p> <p>Where the person has lost the ability to engage with and understand the concept of PDS, making use of previous wishes, and carer/family input can be a source of evidencing that the person has still had an influence over their PDS.</p> <p>Feedback from individuals on their experience of PDS.</p>  |
| b)  | <p>Where the service is refused, notes evidence number of attempts to encourage the person to take up the support, and discussions with the carer, before the case is closed or referred on to another service. The case should not be closed at 'first refusal'. It is common for the person with dementia to decline support when first offered. The PDS practitioner needs to be prepared for this and take time to build a relationship with the person and gain trust. Consideration should also be given to how the carer can either be supported by the service or referred to other sources of carer support.</p>   |
| c)  | <p>Support planning and notes clearly evidence what is important to the person and those who care for them along with any other significant information that has informed decision-making.</p> <p>Feedback from the person and those who care for them on feeling listened to and supported.</p>  |
| d)  | <p>Support-planning assessments evidence an asset-based approach whereby strengths and abilities are identified and what matters to the person is recorded along with any goals and wishes they may have. The service may also refer or introduce the person to other supports and resources to maximise their abilities, to self-manage and to access rehabilitation, for example occupational therapy, physiotherapy, speech and language therapy, technology champions, self-management apps, Alzheimer Scotland's <a href="#">self-management resources</a>. Also consider <a href="#">Brain Health and Dementia Resource Centres</a> at Alzheimer Scotland and <a href="#">Meeting Centres Scotland</a> local meeting centres.</p> |
| e)  | <p>Support-planning assessments evidence an asset-based approach whereby the person's existing hobbies and interests are identified, and strategies are in place to maintain these valued activities, an example might be identifying reading aids if the person is needing support to pursue this interest.</p>  |

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| f)   | Support-planning assessments evidence an asset-based approach whereby the person's community of choice and natural networks are identified, and strategies are in place to maintain these connections.  |
| g)   | Support-planning assessments may identify communication needs and best approaches and/or the PDS practitioner knows where to access advice on the different approaches to supporting communication in dementia, for example speech and language therapy.  |
| h)   | Feedback from those who care for the person on feeling listened to and supported and how the PDS service is making a difference to them.<br>Carer education, formal or informal, should be a key element of carer support and be documented and evaluated.  |
| <b>5. I feel better about the future knowing I have made plans</b> |   |
| <b>Quality criteria</b>  | <b>Suggested evidence</b>   |
| a)   | <p>Evidence might include a record of any training or study the PDS practitioner has undertaken to equip them to discuss and support the person with future planning.</p> <p>Other evidence could be personal plans, Powers of Attorney, Anticipatory Care Plans, benefits claims, referrals to other agencies such as housing if the person's home may not suit them for much longer and a move could be considered. Discussions about housing should take place as early as possible in personal planning conversations.</p>  |
| b)   | <p>Supporting people to develop a personal plan is a component of the Local Delivery Plan standard. A personal plan can take many formats; there is not one set format or template for this. The plan may comprise of several pieces of information used at appropriate times, for example beginning with a <a href="#">Getting to Know Me</a> document or music playlist, such as <a href="#">Playlist for Life</a>. Gathering this information can be a good introduction to the concept of developing a more detailed personal plan to assist with living well, informing future support and moving on to documenting coping strategies, future wishes and anticipatory care planning. A service may have evidence of checking their personal planning practice against the <a href="#">Essential 5 Criteria</a> (see <a href="#">Appendix 3</a>).</p> <p>Where people are unable to engage with the concept of a personal plan then the PDS practitioner could evidence reference to past wishes and carer input to inform the personal plan. What is important to the person and how they wish to live can still be discussed and added to any plans to best reflect the person's thoughts and wishes.</p> |

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| c)   | <p>Evidence of information given and/or support on benefits claims, support for making a will and for accessing self-directed support.</p> <p>Feedback from the person and those who care for them.</p>  |
| d)   | <p>Evidence that practitioners are aware of the importance of supporting the person to have a Power of Attorney (POA) in place. This is a key element of PDS and can help to prevent issues such as delayed discharge from hospital if put in place as early as possible. See these useful resources:</p> <ul style="list-style-type: none"> <li>• <a href="http://mypowerofattorney.org.uk">mypowerofattorney.org.uk</a></li> <li>• <a href="#">Power of Attorney   Alzheimer Scotland</a></li> <li>• <a href="https://www.mygov.scot/power-of-attorney">https://www.mygov.scot/power-of-attorney</a></li> <li>• <a href="#">Office of the Public Guardian</a></li> </ul> <p>Personal planning should evidence POA activity.</p>  |
| e)   | <p>Practitioners can undertake <a href="#">Confident Conversations About Research</a> training provided by the Dementia Neuroprogressive Network, NHSScotland and can access their Confidence Conversations Toolkit. Evidence that practitioners are aware of where to signpost people to, for example, <a href="#">Alzheimer Scotland Dementia Research Centre</a>, if they enquire about participating in research, a common one being about donating brain tissue to research following the person's death.</p>   |
| f)   | <p>Evidence that information, relevant for the individual's Key Information Summary (KIS) held by the GP, has been passed on where appropriate and with the person's consent. The KIS is a widely recognised tool with potential to share important information securely but widely across the system. KIS has been increasingly shown to have a strong link with good anticipatory care planning and palliative care<sup>15</sup>.</p> <p>Relevant information would include PDS input and information from the individual's personal plan particularly if it includes anticipatory care planning details. Lothian HSCP has produced a <a href="#">Dementia Post-Diagnostic Support Link Worker Future Care Planning Bundle</a> to support this process. This bundle, at the bottom of the webpage, can be adapted for local use.</p> |
| <b>6. I have appropriate support that meets my needs as a younger person with dementia</b> |  |
| <b>Quality criteria</b>  | <b>Suggested evidence</b>  |
| a)   | <p>The PDS Service informs all settings where dementia diagnosis takes place for the people in its catchment area of the PDS service that can be provided and how to refer. Consider, for example, if Neurology clinics have been informed that the service is available, give them information leaflets and a key contact. With the person's permission, inform services who support the person of any PDS input.</p>   |

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|    | <p>The dementia practitioners, clinicians, social services, and charitable organisations should work together closely to provide a comprehensive service for people with young onset dementia and their families<sup>17</sup>.</p> <p>People with young onset dementia benefit most from a multidisciplinary approach to care co-ordination including key workers who can refer them to age-appropriate services<sup>18</sup>.</p>  |
| b) | <p>Once a person has been referred to the PDS service and it is apparent that they need urgent input, for example has a rapidly deteriorating dementia or is in a complex or high risk situation that the service could mitigate with quick intervention, then the service can demonstrate that it has the ability to triage and prioritise referrals rather than operate a standard 'first come first served' waiting list. It is important to recognise that, for a variety of reasons, people with young onset dementia may wait twice as long for a diagnosis than older people with dementia<sup>18, 19</sup>.</p> <p>The progression of clinical presentation and functional decline is far more rapid and severe in young onset dementia compared to later onset dementia. People with young onset dementia also present with more behavioural and personality changes earlier<sup>20</sup>.</p> |
| c) | <p>Practitioners are aware of supports, networks and information specific to young onset dementia such as <a href="#">Rare Dementia Support</a> and being a member of the <a href="#">Young Onset Dementia Network</a>.</p>   |
| d) | <p>For support and activities to be considered age-appropriate, the content, locations, and timings of those activities must be specifically designed to be helpful and accessible to younger people<sup>17</sup>.</p> <p>Evidence in personal planning notes that the person has been supported to engage in age-appropriate opportunities that are meaningful to them, including access to similar age peer support.</p> <p>Feedback from the person and those who care for them.</p>   |
| e) | <p>Dementia practitioners from the multi-disciplinary team may be able to suggest resources or support for talking to children about dementia, including counselling for young carers. It may be helpful to inform a child's school or college so support can be put in place.</p> <p>If a person has been diagnosed with a genetic form of dementia, their children could develop it later on. A dementia practitioner from the multi-disciplinary team may be able to refer to genetic counselling for advice if appropriate, Dementia UK's specialist helpline can assist with this<sup>17</sup> (<a href="#">Dementia UK, Young onset dementia: next steps after a diagnosis</a>).</p>  |



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|    | See <a href="#">The milk's in the oven: a booklet about dementia for children and young people</a> . This resource contains links to other resources for young carers.   |
| f) | <p>If the person with dementia is still working, they should inform their employer as soon as possible to ensure they are protected under the Equality Act. In certain types of jobs, the person may be contractually required to tell their employer so that no one is put at risk.</p> <p>Carers may want to inform their own employer of the diagnosis so they can be supported with flexible working arrangements, carers leave and other adjustments that may be helpful (Dementia UK).</p> <p>Evidence in personal planning notes where the person has been supported in relation to employment such as support to communicate with employers where appropriate. Useful resources for the practitioner and person to read are:</p> <ul style="list-style-type: none"> <li>• <a href="#">Work after a diagnosis of dementia</a> by Martin Robertson.</li> <li>• <a href="#">Working with Dementia – Information for employees with dementia</a> by UWS.</li> </ul> <p>Feedback from the person and those who care for them.</p> |
| g) | <p>As the benefits landscape is complex for people with young onset dementia, the post-diagnostic support practitioner can link the person and those who care for them to appropriate benefits advice. Alzheimer Scotland has a very useful <a href="#">Money and Legal Matters</a> webpage.</p> <p>Feedback from the person and those who care for them.</p> <p>People with young onset dementia may still be working, paying a mortgage or other debts, or have younger children to support. Research shows that many people experience financial difficulties, a loss of income, and loss of pension contributions after diagnosis. There are multiple potential sources of financial support, but families living with young onset dementia often do not know how to access these. They need detailed support to help navigate these systems, as well as information and advice<sup>18</sup>.</p>  |
| h) | <p>It is common for the person with dementia to decline support when first offered. The PDS practitioner needs to be prepared for this and take time to build a relationship with the person and gain trust.</p>   |
| i) | <p>The post-diagnostic support practitioner can recognise the signs of poor mental health such as loneliness, apathy, withdrawal from society etc. and can deal sensitively with these issues. There should be a clear pathway for the practitioner to follow for referring the person for additional mental health support.</p> <p>Research shows that people diagnosed under the age of 65 are at a greater risk of suicide, especially in the first 3 months following diagnosis<sup>21</sup>.</p>  |

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|    | PDS practitioners should have access to suicide prevention training to be able to recognise when someone may be thinking about suicide and what to do about it.  |
| j) | <p>Both the person and their spouse or partner should have support with the changes in their relationship, including access to counselling or support groups. Carers of people with young onset dementia are more likely to be employed or have children living at home, which presents unique challenges<sup>17</sup>. The person and the carer may also have caring responsibilities for their parents which brings extra complexities to the family circumstances.</p> <p>Support planning may include information on carer education, carer support groups, carer centres, information given to carers about dementia and coping strategies.</p> <p>Feedback from those who care for the person on how the PDS service is making a difference.</p> |
| k) | Evidence in personal planning notes that the person has been supported to appropriately manage fears, risks and challenges in relation to aspects of their life that are affected by losing skills at a younger age and faster pace. These areas could include driving, working, caring for family and identifying age-appropriate sources of support.   |
| l) | The post-diagnostic support practitioner is included in multi-disciplinary discussions about the people on their caseload. Support and supervision format affords time for emotional support for the practitioner, reflection on complex situations, personal outcomes-focused approaches and includes caseload supervision.   |

## Appendix 2: Improvement plan example template

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| <b>Service name:</b>                            |             | <b>Date:</b>   |                       |
| <b>The top three priorities for improvement</b> | <b>Lead</b> | <b>By when</b> | <b>Date completed</b> |
|   |             |                |                       |
|   |             |                |                       |
|   |             |                |                       |
| <b>Any other improvements</b>                   | <b>Lead</b> | <b>By when</b> | <b>Date completed</b> |
|   |             |                |                       |
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## Appendix 3: Key policies, principles, rights and standards informing the delivery of high-quality post-diagnostic Support

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| <b>Authors</b>  | Alzheimer Scotland, COSLA and Scottish Government  |
| <b>Title</b>  | Scotland's National Dementia Strategy 2017-2020  |
| <b>Available</b>  | <a href="http://www.gov.scot/Resource/0052/00521773.pdf">www.gov.scot/Resource/0052/00521773.pdf</a> |
| <p>The strategy maintains a focus on improving the quality of care for people living with dementia and their families through work on diagnosis, including post-diagnostic support; care co-ordination during the middle stage of dementia; end of life and palliative care; workforce development and capability; data and information; and research. Crucially, within this strategy, there is a recognition of the importance of taking a person-led and flexible approach to providing support at all stages of the care journey.</p> |  |

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| <b>Authors</b>   | Alzheimer Scotland   |
| <b>Title</b>   | 5 Pillars Model of Post-Diagnostic Support   |
| <b>Available</b>   | <a href="http://www.alzscot.org/campaigning/five_pillars">www.alzscot.org/campaigning/five_pillars</a> |
| <p>This model sets out how people newly diagnosed with dementia should be supported by a named professional delivering post-diagnostic support with respect to:</p> <ul style="list-style-type: none"> <li>• Understanding the illness and managing the symptoms</li> <li>• Supporting community connections</li> <li>• Planning for future care</li> <li>• Planning for future decision-making, and</li> <li>• Peer support.</li> </ul> |  |

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| <b>Authors</b>  | Alzheimer Scotland   |
| <b>Title</b>  | 8 Pillars Model of Community Support   |
| <b>Available</b>  | <a href="http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support">www.alzscot.org/campaigning/eight_pillars_model_of_community_support</a> |
| This model sets out a comprehensive and evidence-based approach to the integrated support of people with dementia living at home or a homely setting during the moderate to severe stages of the illness. |  |

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| Authors   | Alzheimer Scotland   |
| Title   | Connecting People, Connecting Support                        |
| Available   | <a href="http://www.alzscot.org/ahp">www.alzscot.org/ahp</a> |
| <p>This framework is about AHPs in Scotland maximising their contribution to supporting people with dementia and their families, partners and carers to live positive fulfilling and independent lives. It features as one of the key commitments outlined in Scotland's third national dementia strategy (2017-2020).</p> <p>See the most up to date range of Alzheimer Scotland AHP resources <a href="#">here</a>.</p> <p>In November 2024, Alzheimer Scotland and Scottish Government launched the third AHP report in dementia called <a href="#">Connecting People, Connecting Support: looking back, looking ahead</a>. An update report on transforming the allied health professions' contribution to supporting people living with dementia, their families and carers in Scotland. The report shares the progress to date and describes what has happened since Connecting People, Connecting Support in action was published in 2020.</p> |  |

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| <b>Authors</b>  | Alzheimer Scotland   |
| <b>Title</b>  | Money and legal matters  |
| <b>Available</b>  | <a href="https://www.alzscot.org/living-with-dementia/money-and-legal-matters">https://www.alzscot.org/living-with-dementia/money-and-legal-matters</a><br><br>Power of attorney information sheet:<br><br><a href="https://www.alzscot.org/sites/default/files/2022-10/Powers%20of%20attorney_October%202022.pdf">https://www.alzscot.org/sites/default/files/2022-10/Powers%20of%20attorney_October%202022.pdf</a> |
| Web page with links to resources about free personal and nursing care, decisions about future treatment, arranging power of attorney, and living with dementia. |  |

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| <b>Authors</b>   | COSLA and Scottish Government   |
| <b>Title</b>   | Dementia in Scotland: Everyone's Story  |
| <b>Available</b>   | <a href="https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/">https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/</a> |
| <p>The strategy sets out a positive, shared vision for dementia in Scotland over the next 10 years. It makes clear the importance of a shared vision that is owned by all of us working together to deliver a better experience for people living with dementia, their families and carers. It builds on several years of globally recognised public policy on dementia in Scotland and commits to ongoing reflection and learning, greater inclusion and delivery from the start.</p> |   |

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| <b>Authors</b>  | Cross Party Group in the Scottish Parliament 2009  |
| <b>Title</b>  | Charter of Rights for People with Dementia and their Carers in Scotland  |
| <b>Available</b>  | <a href="http://alzscot.org/Charter%20of%20Rights%20for%20People%20with%20Dementia%20and%20their%20Carers%20in%20Scotland.pdf">Charter of Rights for People with Dementia and their Carers in Scotland (alzscot.org)</a> |
| <p>The charter is guided by a human rights-based approach (known as the <b>PANEL</b> approach, endorsed by the United Nations). It emphasises the rights of everyone as below.</p> <p><b>Participate</b> in decisions which affect their human rights.</p> <p><b>Accountability</b> of those responsible for the respect, protection and fulfilment of human rights.</p> <p><b>Non-discrimination</b> and equality.</p> <p><b>Empowerment</b> to know their rights and how to claim them.</p> <p><b>Legality</b> in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements.</p> |  |

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| <b>Authors</b>  | Healthcare Improvement Scotland   |
| <b>Title</b>  | The Essential 5 Criteria Bundle   |
| <b>Available</b>  | <a href="https://www.his.scot.nhs.uk/essential-5-criteria-bundle-and-implementation-guide-on-personalised-planning-for-future-care.pdf">essential-5-criteria-bundle-and-implementation-guide-on-personalised-planning-for-future-care.pdf</a> |
| <p>This bundle clarifies the expected minimum level of personalised planning for the future care of people with dementia, supported by the designated post-diagnostic support</p> |   |

practitioner delivering post-diagnostic support and involving carers, families and others close to the person. It is divided into the following five criteria:

- Person is at the centre of the plan
- Personal outcomes
- Person has ownership of the plan
- Personal resilience, and
- Plan is reviewed.

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| <b>Authors</b>   | NHS Health Scotland and Alzheimer Scotland  |
| <b>Title</b>   | Dementia and Equality - meeting the challenge in Scotland   |
| <b>Available</b>   | <a href="https://www.alzscot.org/sites/default/files/images/0003/0229/Spotlight_on_Dementia_and_Equalities.pdf">https://www.alzscot.org/sites/default/files/images/0003/0229/Spotlight_on_Dementia_and_Equalities.pdf</a> |
| <p>This report was compiled by the National Advisory Group on Dementia and Equality and provides recommendations for providing high quality support to everyone with dementia in Scotland. It lays out the following four themes:</p> <ul style="list-style-type: none"> <li>• Continue to raise awareness</li> <li>• Ensure robust services and support pathways</li> <li>• Ensure appropriate knowledge and skills, and</li> <li>• Research.</li> </ul> <p>Three priority recommendations are also detailed for each of the following five population groups with characteristics protected by the Equality Act 2010, where challenges might arise in the context of dementia:</p> <ul style="list-style-type: none"> <li>• Age – younger onset dementia (under the age of 65 years)</li> <li>• Race and ethnicity – black or minority ethnic (BME)</li> <li>• Learning disabilities</li> <li>• LGBT, and</li> <li>• Disability – sensory impairment.</li> </ul> |   |

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| <b>Authors</b>  | NHSScotland, The Scottish Government, Alzheimer Scotland, Scottish Fire and Rescue Service, Tunstall and Tynetec  |
| <b>Title</b>  | Technology Charter for People Living with Dementia in Scotland 2015   |
| <b>Available</b>  | <a href="https://www.alzscot.org/sites/default/files/images/0002/0289/Technology_Charter_for_People_with_Dementia_in_Scotland.pdf">https://www.alzscot.org/sites/default/files/images/0002/0289/Technology_Charter_for_People_with_Dementia_in_Scotland.pdf</a> |
| <p>The Technology Charter for People Living with Dementia in Scotland 2015 follows on from the Charter of Rights for People with Dementia and their Carers in Scotland (Cross Party</p> |   |

Group in the Scottish Parliament 2009) and aims to support achievement of the National Health and Wellbeing Outcomes and the 20/20 Vision for Scotland. The Technology Charter for People Living with Dementia in Scotland 2015 is written to drive change and support the implementation of:

- Scotland's National Dementia Strategies (2010, 2013, 2016 and onwards)
- Standards of Care for People with Dementia in Scotland (2011)
- Promoting Excellence (2011)
- Existing Models of Dementia Care and Support (Post-Diagnostic Support, 5 Pillars Model and 8 Pillars Model)
- Emerging, and future, nationally agreed Models of Dementia Care and Support
- National and local housing policies and strategies, and
- National Technology Enabled Care Programme workstreams.

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| <b>Authors</b>  | Scottish Government   |
| <b>Title</b>  | Carers' charter: Your rights as an adult carer or young carer in Scotland   |
| <b>Available</b>  | <a href="https://www.gov.scot/publications/carers-charter/">https://www.gov.scot/publications/carers-charter/</a> |
| <p>The Carers (Scotland) Act 2016 came into force on 1 April 2018. This act strengthened the rights of carers in Scotland and in particular, aims to improve their health and wellbeing.</p> <p>This charter is designed to make carers aware of their rights under this act.</p> |   |

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| <b>Authors</b>   | Scottish Government   |
| <b>Title</b>   | Health and Social Care Standards: my support, my life   |
| <b>Available</b>   | <a href="https://www.gov.scot/publications/health-social-care-standards-support-life/">https://www.gov.scot/publications/health-social-care-standards-support-life/</a> |
| <p>These Health and Social Care Standards set out what people should expect when using health, social care or social work services in Scotland. They seek to provide better outcomes for everyone; to ensure that individuals are treated with respect and dignity, and that the basic human rights we are all entitled to are upheld.</p> |   |



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| <b>Authors</b>  | Scottish Government   |
| <b>Title</b>  | Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland's National Dementia Strategy |
| <b>Available</b>  | <a href="http://www.gov.scot/Resource/Doc/350188/0117212.pdf">www.gov.scot/Resource/Doc/350188/0117212.pdf</a>            |
| <p>These standards set out the following rights for people with dementia.</p> <ul style="list-style-type: none"> <li>• I have the right to be regarded as a unique individual and to be treated with dignity and respect.</li> <li>• I have the right to access a range of treatment, care and supports.</li> <li>• I have the right to be as independent as possible and be included in my community.</li> <li>• I have the right to have carers who are well supported and educated about dementia.</li> <li>• I have the right to end of life care that respects my wishes.</li> </ul> |   |

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| <b>Authors</b>   | Healthcare Improvement Scotland  |
| <b>Title</b>   | Ageing and Frailty Standards   |
| <b>Available</b>   | <a href="http://Ageing-and-Frailty-Standards-November-2024.pdf">Ageing-and-Frailty-Standards-November-2024.pdf</a> |
| <p>These standards are for the care of older people living with frailty. They apply in all settings where older people living with frailty receive health and social care. They provide a benchmark for progress towards nationally consistent integrated frailty services that put people and their rights at the centre.</p> |  |

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| <b>Authors</b>  | Scottish Government   |
| <b>Title</b>  | Getting it right for everyone (GIRFE) 'team around the person' toolkit  |
| <b>Available</b>  | <a href="https://www.gov.scot/publications/getting-it-right-for-everyone-girfe/">https://www.gov.scot/publications/getting-it-right-for-everyone-girfe/</a> |
| <p>A proposed multi-agency approach to health and social care support from young adulthood to end of life care. GIRFE principles are:</p> <ul style="list-style-type: none"> <li>• I have the information I need to make decisions about my life, in a way that works for me, and I am supported to understand what options are available to me, and trusted to know what is right for me</li> <li>• the people who support me take the time to listen and understand me as a person and we consider my whole life when making decisions about my life</li> <li>• I know that I can be clear about what matters to me, and I trust that my choices will be respected and understood by the people who support me</li> <li>• if I need to access services or support, I am treated with kindness, dignity and respect at all times.</li> </ul> |   |

- the people I am involved with work together with me and each other to share information, in a way that is accessible to me and develop a clear understanding of how to support my wellbeing.

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| <b>Authors</b>  | Scottish Social Services Council, NHS Education for Scotland                              |
| <b>Title</b>  | Equal Partners in Care (EPiC): Practice guidance for working with carers and young carers |
| <b>Available</b>  | <a href="#">Equal partners in care   NHS Education for Scotland</a>                       |
| EPiC is the national framework for workforce learning and development related to unpaid carers. It comprises of a set of core principles which are based on six outcomes for carers and young carers. The framework also has associated learning modules. |   |

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| <b>Authors</b>   | Scottish Social Services Council                                     |
| <b>Title</b>   | Personal Outcomes Planning   |
| <b>Available</b>   | <a href="#">Personal outcomes - Scottish Social Services Council</a> |
| <p>This is a useful resource for people working to put personal outcomes at the heart of what they do day to day. A personal outcomes approach:</p> <ul style="list-style-type: none"> <li>• aims to shift engagement with people who use services away from service-led, input-orientated approaches by working towards specific outcomes identified by the person</li> <li>• is used in assessment, planning, review and evaluation</li> <li>• involves everyone working together to support the person to have the best quality of life possible, and</li> <li>• involves the person in identifying and working towards his or her outcomes, which is critical to the approach and will support and promote individuals' independence, quality of life and well-being.</li> </ul> |  |

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| <b>Authors</b>   | Scottish Social Services Council, NHS Education for Scotland and Scottish Government   |
| <b>Title</b>   | PROMOTING EXCELLENCE 2021: A framework for all health and social services staff working with people with dementia, their families and carers   |
| <b>Available</b>   | <a href="http://www.gov.scot/publications/promoting-excellence-2021-framework-health-social-services-staff-working-people-dementia-families-carers/documents/">www.gov.scot/publications/promoting-excellence-2021-framework-health-social-services-staff-working-people-dementia-families-carers/documents/</a> |
| The framework sets out the knowledge and skills all health and social care staff should achieve in their roles in supporting people with dementia, their families and carers. It works alongside other standards and frameworks, such as the NHS Knowledge and Skills Framework, the Social Services Continuous Learning Framework and the National Occupational Standards for Health and Social Care. The framework also has relevance and applicability to other sectors, such as housing. |  |

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| <b>Authors</b>  | Scottish Social Services Council and NHS Education for Scotland  |
| <b>Title</b>  | Promoting excellence in supporting people through a diagnosis of dementia  |
| <b>Available</b>  | <a href="http://www.nes.scot.nhs.uk/media/nkifgsye/supporting_people_through_a_diagnosis_of_dementia.pdf">www.nes.scot.nhs.uk/media/nkifgsye/supporting_people_through_a_diagnosis_of_dementia.pdf</a> |
| This 'enhanced practice' resource produced by NHS Education for Scotland (NES) advocates a personal outcomes-focused approach to supporting people with dementia and their carers before, during and following a diagnosis of dementia. |  |

## Participation resources

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| <b>Authors</b>   | The Dementia Engagement and Empowerment Project  |
| <b>Title</b>   | Tips for organisations wanting to consult people with dementia about written documents   |
| <b>Available</b>   | <a href="http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf">dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf</a> |
| This guide provides tips for organisations wanting to consult with people with dementia about written documents. |  |

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| <b>Authors</b>   | Healthcare Improvement Scotland Community Engagement   |
| <b>Title</b>   | Participation Toolkit  |
| <b>Available</b>   | <a href="http://www.hisengage.scot/equipping-professionals/participation-toolkit/">www.hisengage.scot/equipping-professionals/participation-toolkit/</a> |
| This toolkit supports NHS staff to involve patients, carers and members of the public in their own care and in the design and delivery of local services. It offers a number of tried and tested tools along with some more recently developed approaches. |  |

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| <b>Authors</b>  | Healthcare Improvement Scotland   |
| <b>Title</b>  | Future Care Planning Toolkit (previously Anticipatory Care Planning)  |
| <b>Available</b>  | <a href="https://ihub.scot/project-toolkits/future-care-planning-toolkit/future-care-planning-toolkit/tools-and-resources/">https://ihub.scot/project-toolkits/future-care-planning-toolkit/future-care-planning-toolkit/tools-and-resources/</a> |
| This guidance has been developed to help health and social care professionals to support individuals who would benefit from Future Care Planning. |   |

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