# The Post-diagnostic Support Quality Improvement Framework

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| 1. I experience high quality post-diagnostic support at the right time and at the right level for me | | |
| Quality criteria for the service (how to support the above outcome) | Rate 1-6 | Evidence/comments |
| 1. Post-diagnostic support is offered, planned and delivered at a pace that reflects the person’s needs and priorities. |  |  |
| 1. 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. |  |  |
| 1. The service has approved arrangements in place for using technology to connect with individuals and follows best practice principles when using virtual methods. |  |  |
| 1. There is equitable access to the service. |  |  |
| 1. The service can provide support that is culturally sensitive. |  |  |
| 1. Information about the service is provided in a language and format that is easy to understand. |  |  |

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| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. The service has approved arrangements in place for sharing personal information appropriately. |  |  |
| 1. 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. |  |  |
| 1. The post-diagnostic support practitioner has a clear understanding of the roles of other professionals and can refer and support access to these. |  |  |
| 1. 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 applicable, prepare for being discharged from post‑diagnostic support. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |

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| 2. I am confident in the people who support me following my diagnosis | | |
| Quality criteria for the service (how to support the above outcome) | Rate 1-6 | Evidence/comments |
| **The practitioner delivering post-diagnostic support:**   1. Has a clear remit and dedicated time and resources to carry out their role. |  |  |
| 1. 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. |  |  |
| 1. Has the key knowledge and skills to support the person and those who care for them as outlined in the Promoting Excellence resources10, 11. This includes the ability to engage with the person via technology if the person chooses this as a preferred method. |  |  |
| 1. Is reliable, proactive and creative, providing consistent support at a pace that reflects the person’s post-diagnostic support needs. |  |  |
| 1. 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 Question12 to help capture an overall measure of the difference post-diagnostic support makes. |  |  |
| 1. Supports the person to keep in touch with contacts who can provide support. |  |  |
| 1. Informs the person and those who care for them about available activities, local opportunities and online resources and, where required, supports access to these. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. Can provide information about accessing and using technology to connect with others and on assistive technology to promote independence for as long as possible. |  |  |
| 1. Receives regular support and supervision which allows for reflection on personal outcomes-focused approaches and supervision of caseload. |  |  |
| 1. Has access to peer support networks, post-diagnostic support resources and appropriate administrative support to keep administrative tasks to a minimum. |  |  |
| 1. 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. |  |  |
| 1. Understands the national commitment13 to post-diagnostic support and how their role contributes to meeting the commitment8. |  |  |

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| 3. I know more about my dementia and have adjusted to my diagnosis | | |
| Quality criteria for the service (how to support the above outcome) | Rate 1-6 | Evidence/comments |
| 1. The post-diagnostic support practitioner has, or can access, the necessary knowledge to be able to provide the person and those who care for them with information on the type of dementia that affects them. |  |  |
| 1. 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 Protocol14. |  |  |
| 1. Support is provided to enable the person to attend to physical health needs where appropriate. |  |  |
| 1. 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. |  |  |
| 1. The person and their carer have access to peer support. |  |  |

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| 4. I feel listened to and what matters to me is at the heart of decisions about me | | |
| Quality criteria for the service (how to support the above outcome) | Rate 1-6 | Evidence/comments |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. The person is empowered and enabled to make the most of their strengths and achieve what matters to them. |  |  |
| 1. The person is supported to continue to be included in their community. |  |  |
| 1. The person is supported to maintain doing activities that are important to them. |  |  |
| 1. 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. |  |  |
| 1. Those who care for the person are listened to and supported in their caring role. |  |  |

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| 5. I feel better about the future knowing I have made plans | | |
| Quality criteria for the service (how to support the above outcome) | Rate 1-6 | Evidence/comments |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. The person and those who care for them are supported to set up Power of Attorney arrangements. |  |  |
| 1. 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. |  |  |
| 1. 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)15. |  |  |

**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.**

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| 6. I have support that meets my needs as a younger person with dementia | | |
| Quality criteria for the service (how to support the above outcome) | Rate 1-6 | Evidence/comments |
| 1. The service has good connections with neurology, memory clinics and Adult Mental Health teams to enable seamless referral to post-diagnostic support following diagnosis. |  |  |
| 1. 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. |  |  |
| 1. The post-diagnostic support practitioner knows how to access information on rare dementias and specialised young onset information and support including peer support. |  |  |
| 1. The person is supported to access age-appropriate services and meaningful opportunities. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |

# Improvement plan example template

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| **Service name:** | | | **Date:** | |
| **The top three priorities for improvement** | **Lead** | **By when** | | **Date completed** |
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| **Any other improvements** | **Lead** | **By when** | | **Date completed** |
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