

SIGN 168

Assessment, diagnosis, care and support for people with dementia and their carers

Checklist for provision of information

This is an extract from [SIGN 168 Assessment, diagnosis, care and support for people with dementia and their carers](#).

The checklist below provides examples of the information people with dementia and their carers may find helpful at the key stages of their journey. The checklist was designed by members of the guideline development group, based on their experience and their understanding of the evidence base. The checklist is neither exhaustive nor exclusive.

Diagnosis

Information provided should be accessible and culturally appropriate to the person with dementia and their carer(s).

- Ensure that the person is not alone when they receive the diagnosis.
- If known, discuss the type of dementia the person has been diagnosed with, symptoms and how the condition might progress.
- Offer tailored information based on the stage of dementia at the time of diagnosis. The information should be reiterated to ensure understanding.
- Encourage the person with dementia and their carer(s) to ask questions and allow sufficient time for answering. Questions people may wish to ask include:
 - What is dementia?
 - What impact is the dementia diagnosis likely to have on the physical and mental health of the person with dementia and their carer(s)?
 - What impact is the dementia diagnosis likely to have on relationships with others, for example friends and family?
 - What can people with dementia and their carers expect and what are the potential care pathways?
- If the carer is young, discuss the impact of the dementia diagnosis on their education or employment and other areas of their life.
- Provide positive message about living well with a terminal, life-changing diagnosis of dementia. Discuss the importance of the person with dementia continuing to do things they enjoy doing and how this can help them to live well.
- Discuss the issue of stigma and how it can negatively impact the lives of people living with dementia and their families and carers, particularly as dementia progresses. Offer information on coping strategies.
- Discuss the importance of the person with dementia and their carer(s) participating in anticipatory care planning discussions.
- If appropriate, offer written information, such as leaflets, for people with dementia and their carers to read in their own time.
- Signpost the person with dementia and their carers to third sector organisations, for example charities and voluntary organisations, where they can receive more information about dementia and the support available, including peer support. This includes information about accessing support for mental health (*see section 9.3*).
- Signpost the person with dementia to free education courses, where they can learn more about dementia (*see section 9.4*).
- Discuss the importance of making plans for the person's financial and personal welfare as soon as possible. Discuss the need for power of attorney and guardianship and explain the difference, as well as where to access help to appoint an attorney or guardian.
- Signpost the person with dementia and their carer(s) to statutory and non-statutory organisations that can help with financial matters, such as claiming welfare benefits (*see section 9.2*).

After diagnosis

- Repeat the information given at diagnosis on the long-term impact of dementia on the person and their carer(s) to ensure understanding.
- Discuss any new support needs, such as counselling, for the person with dementia and their carer(s) and how to access these.

- When discussing support needs with carers, be mindful that male carers may be less likely to engage. Reiterate the importance of support needs for both them and the person living with dementia. Carers from ethnic minority groups and those with additional support needs, such as the deaf community, have specific needs around language during discussions.
- When discussing support needs with LGBTQ+ groups and young carers, highlight sources of support relevant to these specific groups (*see section 5*).
- Discuss the following with the person with dementia and their carer(s):
 - symptom management
 - employment issues
 - safety issues, such as safe driving and kitchen safety
 - where to receive financial support.
- Discuss with the person that they will have access to [free personal care](#), should they need and wish to access it
- Discuss living grief with carers and where they can access support.
- If appropriate, inform the person with dementia and their carer(s) that as the condition progresses there could be times when the person with dementia may need to be sectioned under the Mental Health (Care and Treatment) (Scotland) Act (2003).
- Inform the person with dementia and their carer(s) that there is no situation where they should not be included in do-not-resuscitate conversations.
- Highlight the availability of self-directed support and how this can be accessed.
- Continue to signpost the person with dementia and their carer(s) to third sector organisations, for example charities and voluntary organisations (*see section 9.2*), where they can receive more information about dementia and support, including peer support.
- Sources of further information, such as helplines, video guides, written material and websites, should be made available (*see section 9.3*).