The NICE Dementia Quality Standard on Dementia QS1 states that people with dementia should have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named “care coordinator” and addresses their individual needs.

This document supports commissioners and providers of dementia care to meet that Quality Standard.
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This is a guide for
» Commissioners
» Service providers, including health, social care, voluntary and charitable organisations

This guide will be of interest to
» People living with dementia
» Their families and friends
» Practitioners in dementia care

The purpose of this guidance is to
» Describe the key elements of person-centred support planning
» Describe how to write a new support plan

A support plan should capture what is important to the person living with dementia.

Once a support plan is put in place it needs to be reviewed regularly, to reflect changes in needs, wishes and circumstances.

The professional who helps putting the support plan together should assume the person with dementia has capacity and use clinical judgement, using the Mental Capacity Act when needed.

A support plan should:
» Be owned by the person living with dementia and/or the carer
» Define with whom information about the person with dementia can be shared
» Enable the person to keep an overview of what service is provided by whom, how and when
» Create a list of actions, which at any particular time shows what needs doing and who will do it
» Cover future plans as well as immediate concerns.

1. The Mental Capacity Act 2005 (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. | Fact sheet link
Guidance for commissioners on dementia post diagnostic support planning

Who should be involved in support planning?

The person with dementia

Anyone of importance to the person living with dementia should be invited to contribute if the person with dementia wants them to.

A named key professional:

» This person will vary depending on local circumstances and/or the needs of the person and the skill set of the professional.
» A change in circumstances may mean that the key professional role is taken up by a different person.
» The identity of the named key professional needs to be shared with others involved in the support plan.

The key professional should:

» Take the lead in the ongoing process of support planning and communicate the plan with the GP and other relevant people or services, with consent from the person living with dementia or – if not capacitated – their representative.
» Check whether a support or care plan is already in place (either for dementia or for any other condition) and ensure that as far as possible all care and support needs are covered in one care plan.
» Have a good understanding of the principles of person-centred care.
» Have knowledge of local services available locally (for example, via Dementia Connect).
» Take the lead in structuring and reviewing the support plan.
» Ensure services are coordinated around the needs and wishes of the person living with dementia and their carer(s).
» Ensure actions are implemented and reviewed.
» Ensure any carer needs are identified and addressed in line with the 2015 Care Act.
» Have appropriate training, supervision and support, appropriate to their role. (More guidance is available from The Dementia Core Skills Education and Training Framework)
Why and when should support planning take place?

**Purpose**
The purpose of a support plan (and any subsequent review) is to:
» Maximise on abilities and opportunities
» Optimise (self) management
» Ensure care is coordinated
» Plan for the future
» Avoid crises

**It should be offered as soon as possible after diagnosis.**
But timing will vary according to the needs of the person. Some people need “breathing space” and will need support planning to be deferred.

**The person living with dementia and family/carers need to know:**
» That support is available immediately if that is preferred, or at a later date.
» That, if immediate uptake is not desirable, support planning will be offered again, ideally after an agreed interval.
» How to access whomever will assist in support planning.

**Support planning takes time.**
It requires sensitivity around the needs of the individual. It therefore may take more than one meeting to explore all areas relevant to the individual.

**Support plans must be reviewed.**
This should be done on an ongoing basis and updated to reflect any changes in needs and wishes of the person living with dementia and their carer(s).

**The frequency of review may vary.**
The frequency will depend on the needs and wishes of the person with dementia and their carers, and the level of clinical risk. As a minimum, a review should occur within six months of the initial support planning process.
What should a support plan contain?

The support plan should
» Identify and understand the capabilities and activities of the person living with dementia
» Balance the individual's wishes and independence with possible risks, adopting an approach of positive risk-management
» Identify actions that may assist in preserving capabilities and activities as long as possible
» Contain an 'easy read' summary or list of key points and actions as a means of clear communication
» Consider how it links to other support plans, e.g. urgent care plans
» List what actions are to be addressed by whom and, if possible, stipulate a timeframe for completion
» Not just list problems, but focus on solutions and explore opportunities with the person living with dementia and/or the carer
» Facilitate advance care and end of life planning
» Identify possible complications and include appropriate contingency plans which have been discussed with the person living with dementia and/or their carer
» Identify any necessary measures of safety
» Be easy to read, avoiding the use of acronyms and ensuring the language used is dementia friendly.

The support plan should contain
» Life story material
» Sources of information:
  » Symptoms of dementia
  » Coping strategies
  » Medication
  » Local services, including peer support groups, etc
» Legal and financial issues and where to get advice
» What to do when capacity is diminishing or is being lost
» How to access advocacy
» Contact details of the key carer and emergency contact details
» Recent changes in circumstances (e.g. change of address, bereavement or trauma)

The support plan may contain (if appropriate)
» A list of physical health problems
» Where available an 'urgent care plan'
» Past and current mental health problems, other than dementia
» Current medication.
» Content of advance care planning discussions
In which format should the support plan be in, and how should it be shared?

The support plan could be either in electronic or paper format or both.

The format must be what works best for the person living with dementia, their friends and family and the key professionals completing, using and reviewing the support plan.

Sharing of information

The person living with dementia and/or their carer(s) should have control over who can access what in the support plan.

Therefore, mechanisms should be in place for the person living with dementia to:
» Allow access to all or part of the support plan to identified individuals
» Consent to share documents and other relevant information
» Review these arrangements or have them reviewed regularly
» Have their support plan treated as a confidential document in line with data protection principles.
Resources

Refusals of treatment
Compassion in Dying, *Advance decisions to refuse treatment* | Link

Think Local, Act Personal
This is a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support. | Link

NICE quality standards
This standard, QS1, *Dementia: support in health and social care*, defines a high standard of care in this area. | Link

Everyone counts: Planning for patients 2014/15 to 2018/19
This planning guidance published by NHS England outlines a framework within which commissioners will need to work with providers and partners in local government to develop strong, robust and ambitious five year plans. | Link

One chance to get it right
From the Leadership Alliance for the Care of Dying People, this report aims to improve people’s experience of care in the last few days and hours of life. | Link

Dementia Connect
This is the new and improved demential services directory from the Alzheimer’s Society. | Link

Coordinate My Care
CMC is an NHS clinical service, sharing information between healthcare providers, coordinating care and recording wishes of how patients would like to be cared for. | Link

MyBrainBook
Created by IXICO and the Health Innovation Network AHSN, this is a personalised online tool delivering facilitated support to people with dementia, their carers and family. | Link

Dementia core skills education and training framework
This joint project by the Department of Health, Health Education England and Skills for Health sets out the core skills and knowledge which would be transferable and applicable across different types of service provision. | Link

Molly’s story
This video from NHS Berkshire West CCGs provides a carer’s perspective of end of life care for someone with dementia. | Link