

# Dementia – discussing and planning support after diagnosis

A quick guide for people with dementia and their family and carers



*“The right information and support will  
enable us to live better with dementia”*

(Person living with dementia)

A diagnosis of dementia may create very mixed emotions. Coming to terms with it, making decisions and planning ahead are all part of living well with dementia.

Getting information and support when you need it from people working in health and social care can make a real difference.

## What information to expect

When you are diagnosed with dementia you should be offered information relevant to the stage of your condition, including:



This information should be explained to you and given to you in writing. You can ask for it to be provided in a format that you find easy to understand. If you don't need this information straight away you can ask for it when you do.

You should also have the chance to talk about:



**consent...** do you agree to services sharing information about you? Who can they share information with and what are you willing for them to share?



**information...** do you know who to contact for more advice if your needs change?



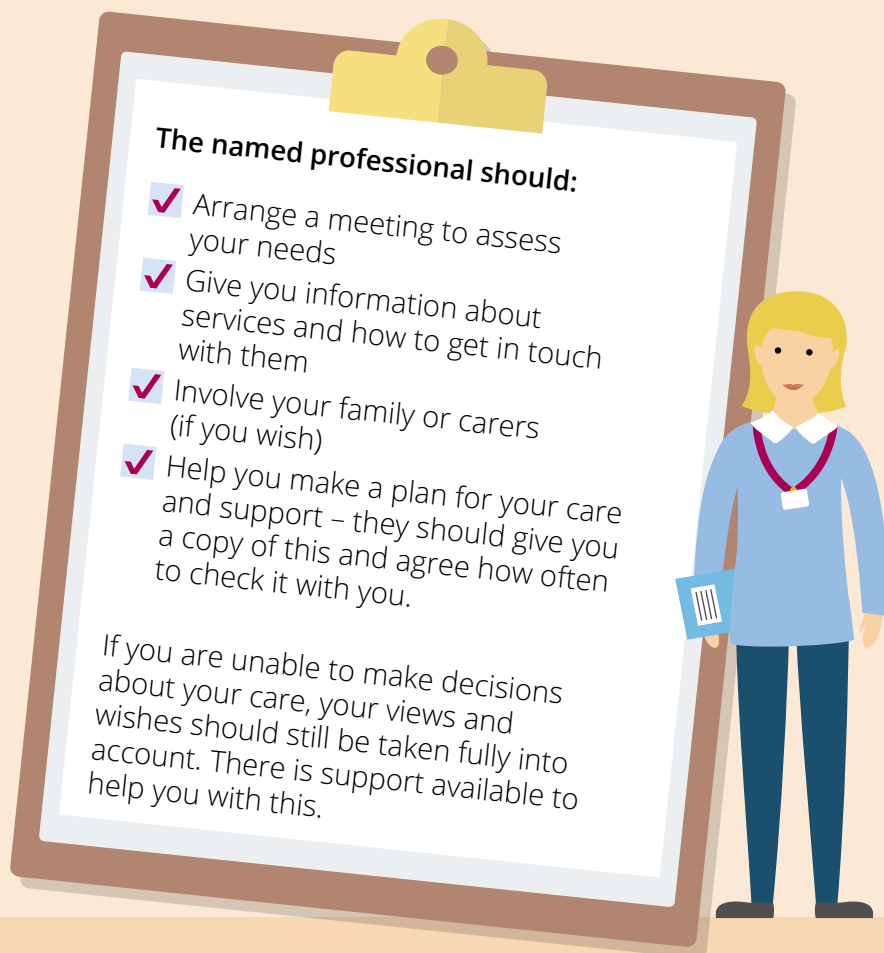
**future contact...** you may not need any help or further appointments now. If that is the case, would you like to be contacted again and if so, when?

## Planning for now

After your diagnosis, you should be directed to the services that can give you more information and support. You should also be given the **name of a professional** who will co-ordinate any care and support you might need.

### Help to express your wishes

You should be told about local advocacy services. An advocate can help you express your needs and wishes. They can help you to understand the different options and to make decisions. They can also help you find services, make sure the correct procedures are followed, and challenge decisions on your behalf.



## Planning for your future

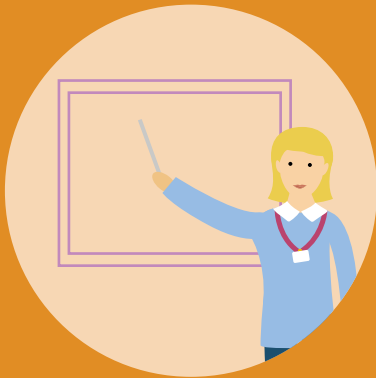
Thinking ahead may feel difficult but advance care planning can be helpful in making sure people are aware of your wishes for the future. When you feel ready for this discussion, you should be offered support and information to discuss:



You should be offered the chance to check that any advance statements and decisions are still right for you each time your care and support is reviewed. You can change any decisions you wish to.

# Support for carers

As a carer for a person living with dementia, you should be offered:



**training** to help you understand dementia, provide care and communicate with the person who has dementia, look after yourself, find out about services, plan activities and think about the future.



**support** that is flexible and right for you and what you want to achieve, that helps you support your relative or friend, and that is available when you need it. This may be as part of a group or online.



**advice** about how to get an assessment of your own needs (a 'carer's assessment') and about how to get a short break or respite care.

## Further information

[Dementia: assessment, management and support for people living with dementia and their carers](#) – NICE guideline

[The dementia guide](#) – Alzheimer's Society Telephone helpline 0300 222 1122

[After diagnosis of dementia: what to expect from health and care services](#)  
– Department of Health and Social Care

[Living with young onset dementia](#) – Young Dementia UK

[Admiral Nurse Dementia Helpline](#) – Telephone 0800 888 6678

[Dementia](#) – SCIE

[Join dementia research](#) – National Institute for Health Research

[Making decisions](#) – Office of the Public Guardian

[Dementia Carers Count](#) – Royal Surgical Aid Society

This content has been co-produced by NICE and SCIE and is based on NICE's guideline on dementia: assessment, management and support for people living with dementia and their carers.

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