



**DementiaUK**

Helping families face dementia

**After a diagnosis  
of dementia  
Understanding and  
challenging stigma and  
discrimination**



## **Living with dementia: next steps after a diagnosis**

**A diagnosis of dementia can be a big shock – for the person with the condition, and their family. It can be difficult to know what to do, what decisions need to be made, who to tell, what support is available and what happens next.**

**Dementia UK provides specialist dementia support for families through our Admiral Nurse service. Admiral Nurses give families the compassionate one-to-one support, expert guidance and practical solutions they need to face dementia with more confidence.**

**This series of leaflets has been written by Admiral Nurses, to help you to make decisions as a family about accessing the support you need, as well as anticipate and manage some common issues.**

## **Understanding and challenging stigma and discrimination**

Being diagnosed with dementia can be upsetting; for the person and for those around them. As well as feeling fearful about how the dementia will impact upon them and their quality of life, some people also feel a sense of stigma or discrimination – worrying that other people may now treat them differently, or even badly.

Understanding why stigma and discrimination happen, and what can be done to reduce and prevent them, is important – for the person living with dementia and for their family, and wider society.

Stigma is a negative or unfair belief that people may hold, which may lead to negative stereotyping and discrimination. Discrimination is unfair treatment that results from the negative stereotype.

When a person is labelled as having dementia, they are often no longer seen as a unique individual but as a part of a stereotyped group of people, which may lead to other people making negative

assumptions about them and treating them poorly as a result.

## Why do stigma and discrimination happen?

Healthcare professionals use particular labels – such as dementia – to classify people; it helps them to organise treatment and research according to the diagnosis. Unfortunately, these labels can also lead to the person experiencing stigma, stereotyping and discrimination.

People are discriminated against for a whole variety of reasons, such as age, disability, gender reassignment, pregnancy and maternity, race, religion or belief,

sex or sexual orientation. All these are listed as protected characteristics under the Equality Act (2010), which makes it illegal for people with protected characteristics to be treated less favourably.

A person diagnosed with dementia may have an increased risk of discrimination due to a combination of the protected characteristics. This is sometimes described as a ‘double jeopardy’ effect.

Stigma and discrimination can happen due to a lack of understanding about dementia and its effects. People might be afraid of the diagnosis itself, or they might not understand that some symptoms are caused by dementia,





and they might blame the person for the way they are behaving – and treat them badly as a result.

Unfortunately, the media contribute to negative stereotyping of people with dementia and therefore discrimination; either by using unhelpful language such as *sufferer*, *dementia time bomb*, *burden*, *death sentence*, or by the way it portrays people living with dementia. This further increases the public's fears about dementia and reinforces negative stereotypes.

### What are the potential effects of stigma and discrimination?

The person displaying symptoms might feel afraid of a diagnosis of dementia. This can lead to them delaying their assessment and diagnosis, sometimes for years – time in which they could be getting treatment and support.

There are many other health conditions with symptoms similar to dementia, but which can be easily treated, including some infections, vitamin or hormone deficiencies, mental health issues and stress. Fear of dementia, due to the stigma, can stop people seeking treatment for these treatable conditions.

Some people with dementia and their families feel embarrassed and ashamed of the diagnosis, due to the perceived stigma and discrimination they will receive from others within the family and social network. This can lead to withdrawal from activities and social interaction and increase loneliness and social isolation.

An accurate, timely diagnosis of dementia is very important, as this can help the person and their family access support and make decisions about their future at an early stage. People with dementia often report that when they are diagnosed, some family and friends reduce their contact or behave differently towards them. This could be due to fear, negative stereotypes or worry that they may say or do “the wrong thing”.

Also, some families become overprotective of the person diagnosed, and believe that things the person can still do may be risky now they have a diagnosis, even though there is lots of evidence that continuing with interests that the person enjoys is beneficial for their well-being.

All the negative stereotypes held by society, family and friends can lead to the person diagnosed with dementia experiencing:

- self-doubt and lack of confidence
- professionals and family talking over them, and about them
- lowered self-esteem and motivation
- negative effects on roles and relationships with family and friends
- friends and family avoiding contact
- segregation e.g. only being able to access specific groups and services for people with dementia, rather than continuing to attend other interest groups
- mental health issues including anxiety and depression
- reduced access to certain useful services, such as talking therapies, rehabilitation
- professionals, and others, holding a negative opinion on their quality of life and their ability to make decisions

## How can stigma and discrimination be prevented or managed?

People living with a diagnosis of dementia and their families have an important role to play in preventing and managing stigma and discrimination.

Here are some examples of ways that you can do this:

- Recognise and focus on the strengths and abilities of the person with dementia; the things that bring you joy, rather than things that are more difficult
- Continue with activities and social contact that you enjoyed before diagnosis, adapting these to fit your present situation if you need to
- Enjoying and celebrating small daily aims, rather than worrying about longer term ones; this will help to develop positive thoughts and actions
- Helping each other find ways to respond to stereotypes and discrimination; using humour to diffuse situations when the negative behaviour of others is problematic
- Encouraging families and friends to talk together and to listen to what is needed: whether this be patience, time, feeling included, or involved in decision making
- Invite family and friends to ask questions about how dementia is affecting you and what they can do to help
- Getting involved in campaigns and groups that challenge discrimination, and sharing the voices of people living with the effects of dementia
- Joining a support group where experiences and approaches can be shared; this can also reduce isolation
- Challenging stereotypes and discrimination when you see them

Every person is different and their experience throughout life will influence how they think, feel and behave. This is no different for people diagnosed with dementia. Living a full life with fun and meaning will not only help the person with dementia to live alongside their condition, but it will help to challenge the stigma others have.

## Sources of support

**Dementia UK resource on Life Story work**

[www.dementiauk.org/life-story](http://www.dementiauk.org/life-story)

**Dementia UK leaflet on the Emotional impact of the diagnosis**

[www.dementiauk.org/emotional-impact-of-the-diagnosis](http://www.dementiauk.org/emotional-impact-of-the-diagnosis)

**Dementia UK leaflet on Changing roles and relationships**

[www.dementiauk.org/changing-roles-and-relationships](http://www.dementiauk.org/changing-roles-and-relationships)

**Dementia UK leaflet on Staying healthy**

[www.dementiauk.org/staying-healthy](http://www.dementiauk.org/staying-healthy)

**Dementia UK leaflet on managing anxiety and depression**

[www.dementiauk.org/managing-anxiety](http://www.dementiauk.org/managing-anxiety)

**Dementia UK tips for better communication**

[www.dementiauk.org/better-communication](http://www.dementiauk.org/better-communication)

## Organisations that may be of use:

**Dementia UK - the Admiral Nurse Dementia Helpline**

[www.dementiauk.org/helpline](http://www.dementiauk.org/helpline)

**Alzheimer's Society**

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

**British Psychological Society**

[www.bps.org.uk](http://www.bps.org.uk)

**Counselling Directory**

[www.counselling-directory.org.uk](http://www.counselling-directory.org.uk)

**Mind**

[www.mind.org.uk](http://www.mind.org.uk)

**Relate**

[www.relate.org.uk](http://www.relate.org.uk)

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email [feedback@dementiauk.org](mailto:feedback@dementiauk.org)

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit [www.dementiauk.org/donate](http://www.dementiauk.org/donate) or call **0300 365 5500**.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Open Monday – Friday, 9am – 9pm  
Saturday and Sunday, 9am – 5pm



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