



DementiaUK
Helping families face dementia

Dealing with stigma and discrimination



When someone lives with dementia, they may experience stigma or discrimination because of people's negative perceptions of what dementia is, who it affects, and how it affects people mentally and physically. This may lead to the person being treated differently, or sometimes, people taking advantage of them.

Stigma is a negative, unfair or inaccurate belief or stereotype that people hold about something. For example:

- “People with dementia cannot work”
- “People with dementia cannot make their own decisions”

Discrimination is poor or unfair treatment that often results from stigma and negative stereotypes. For example:

- The person's performance at work is called into question
- Family members take over decisions that the person is still capable of making themselves

Why do stigma and discrimination happen?

People are discriminated against for a variety of reasons. These include:

- age
- disability
- race
- religion or belief
- sex
- sexual orientation
- gender reassignment
- pregnancy and maternity
- marriage/civil partnership

Under the Equality Act (2010), it is illegal for people with these characteristics to be treated less favourably or discriminated against – and because dementia is considered a disability, people with the diagnosis are legally protected against discrimination.

Stigma and discrimination against people with dementia often result from a lack of understanding about the condition. People might not realise that certain symptoms are caused by a person's dementia and blame them for the way they are behaving – and treat them badly as a result.



For instance, the person may seem uncooperative because they are struggling to understand and communicate, and a family member may think they are being deliberately difficult and become frustrated with them.

Or they might be finding personal care difficult leading to a deterioration in their appearance, meaning family and friends feel embarrassed about being seen with them in public and stop going out with them.

People may also have biased

opinions about dementia and those who are living with it – for example, that they shouldn't be left alone, cannot be trusted to make decisions, or cannot look after themselves.

The media contributes to stigma by using unhelpful language such as 'dementia sufferer', 'demented', 'burden' or 'death sentence', and sometimes, people living with dementia are portrayed in stereotypical ways in TV shows. This can reinforce stigma and discrimination in society as a whole.

Young onset dementia, stigma and discrimination

Around 70,800 people in the UK live with young onset dementia (where symptoms develop before the age of 65), and for these people, stigma and discrimination can be a significant issue.

Often, the early symptoms of dementia in younger people differ from common perceptions of how dementia typically presents. For example, memory problems are less likely in the early stages, but the person may have difficulties with:

- speech and language
- problem-solving
- decision-making
- concentration
- changes in personality and mood

There is also a lack of awareness of young onset dementia. Many people believe that dementia is a condition of old age and don't realise that younger people can be affected. They may not understand that the changes they are seeing are the result of dementia and cannot be controlled, and think

that the person is being 'difficult', 'unreliable' or 'unpredictable'.

For example:

- If someone is making mistakes at work, their employer may start a performance review process or even terminate their employment
- If the person shows reduced empathy and unstable emotions, other people may believe they are being unkind or unfair – this may be especially difficult for children or young people who have a parent with dementia
- Problems with visual perception and spatial awareness may affect the person's driving, with other people thinking they are driving carelessly or recklessly

Stigma and discrimination in minority ethnic communities

Families from Black, Asian and other minority ethnic groups may experience higher levels of stigma and discrimination around dementia – including from within their own communities.



Knowledge and understanding about dementia in these communities is often lacking, and there may be deep-rooted myths and taboos – for example, beliefs that dementia is a result of evil spirits at work, or a punishment for a past wrongdoing.

Alternatively, dementia may be seen as an inevitable part of ageing that people must simply accept, meaning they do not seek help.

In some communities there are significant language barriers. For example, in many South Asian languages, there is no word to describe ‘dementia’ – so instead, people may use words like ‘mad’ or ‘crazy’.

Families may also have strong cultural beliefs around caring that make them reluctant to ask for and accept formal support – such as a sense of duty to care for family members themselves, or a fear of other people thinking they are unable to cope.

This, combined with a lack of specialist, culturally sensitive support and a lack of knowledge of how to access dementia services, can cause additional challenges. For example, a person may be less likely to seek a diagnosis if they are afraid of stigma from the people around them, meaning that they do not get the support they need, leading to crisis situations further down the line.



What are the potential effects of stigma and discrimination?

Stigma, discrimination and negative stereotypes around dementia may mean that a person showing symptoms is afraid of receiving a dementia diagnosis. This can lead to them putting off seeking help, sometimes for years.

In some cases, symptoms may be due to a treatable condition such as an infection, vitamin deficiencies, mental health issues, menopause or stress. If the person delays seeing their GP, they may miss out on potential treatment for these conditions.

If the person does have dementia, a reluctance to seek a diagnosis may delay them accessing treatment and support that could reduce or improve their symptoms, give them and their family a better quality of life, and allow them to make decisions about their future at an early stage.

Some people with dementia feel embarrassed about the diagnosis because of the stigma surrounding it. They may withdraw from activities and social contact, resulting in loneliness and isolation.

Family and friends may also reduce contact with the person or behave differently towards them. This

could be due to fear, negative stereotypes or worries that they may say or do the wrong thing.

Some families also become overprotective and believe that certain activities – such as work, driving or living independently – are too risky, even if the person’s dementia hasn’t yet affected their abilities. They may try to prevent the person doing these activities, affecting their wellbeing and leading to a loss of independence.

Negative stereotypes can lead to the person with dementia experiencing:

- self-doubt and lack of confidence
- professionals and family talking over or about them
- reduced self-esteem and motivation
- changes in roles and relationships with family and friends
- friends and family avoiding contact
- social segregation, eg only being able to access groups

and services for people with dementia, rather than continuing to attend other interest groups

- reduced access to certain useful services, such as talking therapies and rehabilitation
- anxiety and depression
- not being allowed or trusted to make decisions, and people making decisions on their behalf
- a loss of independence – such as people taking over tasks that the person is capable of themselves, leading to a loss of skills and abilities

How can stigma and discrimination be prevented or managed?

People living with dementia and their families have an important role to play in preventing and managing stigma and discrimination. Here are some things to try:

- Encourage the person to share news of their diagnosis with family and friends to reduce speculation about what is ‘wrong’ with them. Invite family

- and friends to ask questions about dementia and how it is affecting the person to reduce misunderstandings and fear
- If the person works, support them to tell their employer about their diagnosis – this will ensure that they are legally protected from discrimination and allow adjustments to be made so they can continue to work, if they wish. Bear in mind that in some jobs, such as the armed forces, healthcare professions and positions that involve driving or using machinery, there is a contractual obligation to inform the employer of a dementia diagnosis – please see Sources of support on p10 for information on employment and dementia
 - Recognise the strengths and abilities of the person with dementia. Focus on what they can still do, rather than what they can't
 - Support the person to continue with their usual activities, with adaptations if necessary, rather than assuming that they should stop
 - Help the person live as fully as possible, within their capabilities – this will not only help them maintain independence and enjoyment in life, but also challenge the stigma around dementia
 - Help each other find ways to respond to stereotypes and discrimination, eg using humour to de-escalate tense situations where people are behaving negatively towards the person, or coming up with some set phrases to use in response to unpleasant comments
 - Do not avoid social or public situations – if people with dementia are 'hidden away', it can perpetuate shame, stigma and a lack of understanding around the condition
 - Encourage family and friends to talk openly and listen to what the person needs
 - Ensure that if a decision needs to be made, the person with dementia is involved as fully as possible. If they lack capacity to make a decision or communicate their views, make sure that the

decision is made in their best interests – please see Sources of support on p10 for information

- If the person is from a minority ethnic background and is experiencing stigma or discrimination within their community, consider asking a faith or other community leader, such as an imam or rabbi, if they could facilitate communication between the person's family members and friends, or speak to them about dementia and how it may affect the person with the diagnosis. Sometimes people find it easier to take advice from someone who holds status in their community
- Avoid being overprotective. If you are concerned that the person may be vulnerable in certain situations, look for ways that they can continue with them safely – for example, if they enjoy cycling but you are worried about them getting lost, you could arrange for a 'buddy' to go with them
- Encourage the person to carry or wear a form of identification to alert members of the public that

they may need support, such as Hidden Disabilities Sunflower lanyard or ID card – see Sources of support on p11

- Get involved in campaigns and groups that raise awareness of dementia to help break down stereotypes and challenge stigma and discrimination; and to share experiences and approaches with people in a similar situation. Please see Sources of support on p11 for information on groups that you may like to join
- Work with the person with dementia to compile a 'life story' – a record of their life that can be shared with family, friends and carers to help them understand more about the person as an individual
- Remember that everyone has their own personal views and experiences that influence how they think, feel and behave, but take opportunities to help others understand that the person with dementia is more than their diagnosis

Sources of support

To speak to a dementia specialist Admiral Nurse about stigma and discrimination or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/book-a-clinic-appointment

Dementia UK resources

Creating a life story
dementiauk.org/life-story

Changing relationships
and roles
[dementiauk.org/
changing-relationships-
and-roles](https://dementiauk.org/changing-relationships-and-roles)

About young onset dementia
[dementiauk.org/about-
young-onset-dementia](https://dementiauk.org/about-young-onset-dementia)

Employment and dementia
[dementiauk.org/
employment-and-young-
onset-dementia](https://dementiauk.org/employment-and-young-onset-dementia)

Managing anxiety
and depression
[dementiauk.org/
managing-anxiety](https://dementiauk.org/managing-anxiety)

Driving and dementia
[dementiauk.org/driving-
and-dementia](https://dementiauk.org/driving-and-dementia)

Mental capacity and
decision-making
[dementiauk.org/capacity-
decision-making](https://dementiauk.org/capacity-decision-making)

Changes in sexual behaviour
[dementiauk.org/changes-
in-sexual-behaviour](https://dementiauk.org/changes-in-sexual-behaviour)

Database of young onset
dementia support groups
and services
[dementiauk.org/
find-support](https://dementiauk.org/find-support)

Dementia UK
Campaigns Network
[dementiauk.org/join-
campaigns-network](https://dementiauk.org/join-campaigns-network)

Other resources
tide: together in dementia
everyday – dementia
training courses and
influencing groups
tide.uk.net



**DEEP – the UK Network of
Dementia Voices**
dementivoices.org.uk

**Acas: disability discrimination
at work**
[acas.org.uk/disability-
discrimination](https://acas.org.uk/disability-discrimination)

**Hidden Disabilities
Sunflower Scheme**
hiddendisabilitiesstore.com

Young Dementia Network
– a network of people
affected by and working
in the field of young
onset dementia
[dementiauk.org/the-young-
dementia-network](https://dementiauk.org/the-young-dementia-network)

**Equality and Human
Rights Commission**
equalityhumanrights.com

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email feedback@dementiauk.org

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We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.



To donate: call **0300 365 5500**,
visit dementiauk.org/donate-to-support
or scan the QR code.

Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.

Helpline: **0800 888 6678** or helpline@dementiauk.org

Virtual clinics: dementiauk.org/book-a-clinic-appointment



dementiauk.org • info@dementiauk.org

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
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