

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”
- “Only old people get dementia”

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 should not 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.

Family and friends of a person with dementia may also indirectly be affected by stigma and discrimination, for example people excluding them from social gatherings because they assume they will not be able to attend because of their caring responsibilities.

Young onset dementia, stigma and discrimination

Over 70,000 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

Younger people are also more likely to have a rarer form of dementia with less widely recognised symptoms, which may lead to people making incorrect assumptions about changes in their personality or behaviour.

There is also a lack of awareness of young onset dementia. Many people believe that dementia is a condition of old age and do not 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 may also indirectly affect the family and friends of a person with young onset dementia. For example, a person may be overlooked for a promotion at work if their employer assumes their caring responsibilities will affect their ability to do

their job. Or a child's friend may not be allowed to visit for a playdate if the friend's parent is worried about them being around the person with dementia.

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 within their own communities.

Knowledge and understanding of dementia in some communities is often variable, and there may be deep-rooted myths and taboos. 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 for 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.

Stigma and discrimination in the LGBTQ+ community

People with dementia who identify as lesbian, gay, bisexual, transgender, queer/questioning or another sexual orientation/identity that falls under the LGBTQ+ umbrella often face a double



stigma as a result of their sexuality/gender identity as well as their dementia.

As a result, some LGBTQ+ people are wary of accessing health and social care services in case they encounter misunderstanding, judgement or discrimination. They may be reluctant to seek a diagnosis of dementia and post-diagnostic support, which could negatively impact their overall health, wellbeing and independence.

LGBTQ+ people who are living with dementia may also have anxieties around accessing support groups or social activities due to fear of judgement or negative attitudes from other participants. This can lead to social isolation.

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 deficiency, 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 their 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 become overprotective and believe that certain activities – such as work, driving or living independently – are too risky, even if the person's dementia has not yet affected these abilities. They may try to prevent the person continuing with 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



- family and friends 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:

- Take some time to educate yourself about dementia. Stigma is often the result of fear and misunderstanding, so developing your knowledge of the condition can help to overcome this. This will help you avoid stigmatising the person with dementia yourself, and enable you to pass on your knowledge to others
- Encourage the person with dementia to tell family and friends about their diagnosis. This could help to reduce speculation about what is ‘wrong’ with them. Invite those close to them to talk openly, ask questions about dementia and how it is affecting the person, and listen to what they need
- 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 p14 for information on employment and dementia
- Recognise the person’s strengths and abilities. Focus on what they can still do, rather than what they cannot
- Support the person to continue with their usual activities. Do not assume that they need to stop as a result of their diagnosis, but be prepared to make adaptations if necessary
- Help the person live as fully as possible. By supporting them to be as active and engaged as possible, within their capabilities, you



will not only help them maintain independence and enjoyment in life, but also challenge the stigma around dementia

- Find ways to respond to stereotypes and discrimination. For example, you or the person with dementia could use humour to de-escalate tense situations where people are behaving negatively towards them, or come 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
- When making decisions, involve the person with dementia 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 p14 for information
- If the person is experiencing stigma or discrimination within their

community, consider asking someone who understands that community's beliefs and values to speak to family members and friends about dementia and how it may affect the person with the diagnosis. This will help them understand more about what is happening so they can better support the person with dementia

- 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 the Hidden Disabilities sunflower lanyard or ID card – see Sources of support on p15
- 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 p13-15 for information on Dementia UK's campaigns and 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. Please see Sources of support on p13.
- 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

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, ‘Dementia: what next?’ Hosted by dementia specialist Admiral Nurses, they cover topics like types of dementia, symptoms, financial and legal issues and planning for the future. Sign up at

➤ dementiauk.org/dementia-what-next

To speak to an Admiral Nurse on our free Helpline, call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email ➤ helpline@dementiauk.org

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit ➤ dementiauk.org/book

Dementia UK resources

Book an appointment with the Consultant Admiral Nurse for the LGBTQ+ Community

➤ dementiauk.org/lgbtqappointment

Changes in sexual behaviour

➤ dementiauk.org/changes-in-sexual-behaviour

Changing relationships and roles

➤ dementiauk.org/changing-relationships-and-roles

Creating a life story

➤ dementiauk.org/life-story

Dementia UK campaigns Network

➤ dementiauk.org/campaigns

Different symptoms of young onset dementia

➤ dementiauk.org/young-onset-dementia-different-symptoms

Driving and dementia

➤ dementiauk.org/driving

Employment and young onset dementia

➤ dementiauk.org/employment

Find young onset dementia support groups and services

➤ dementiauk.org/find-support

Managing anxiety and depression

➤ dementiauk.org/managing-anxiety

Mental capacity and decision-making

➤ dementiauk.org/capacity-decision-making

Supporting children and adolescents when a parent has young onset dementia

➤ dementiauk.org/supporting-children

Understanding young onset dementia

➤ dementiauk.org/about-young-onset-dementia

Other resources

Acas

Free, impartial advice on working rights

➤ acas.org.uk

Citizens Advice

➤ citizensadvice.org.uk

DEEP – the UK Network of Dementia Voices

➤ dementiavoices.org.uk



Equality Act (2010)

➤ gov.uk/guidance/equality-act-2010-guidance

Hidden Disabilities sunflower scheme

➤ hiddendisabilitiesstore.com

Rare Dementia Support

➤ raredementiasupport.org

tide: together in dementia everyday

Dementia training courses and influencing groups

➤ tide.uk.net

Young Dementia Network

An online community of people affected by dementia, their family and friends, and health and social care professionals – hosted by Dementia UK

➤ youngdementianetwork.org

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:
0800 888 6678 or helpline@dementiauk.org

Book a virtual appointment:
dementiauk.org/book

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan the QR code

Thank you.



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